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April 2008

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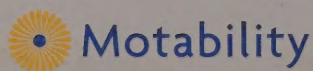
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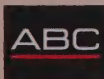
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editorial

As complex as life and death

Once again the general media have got it completely wrong. Previously they've turned the whole welfare to work debate into an exposé on what a bunch of work-shy malingerers we disabled people are. Now they're using the passage of the human fertilisation and embryology bill (HFE) through Parliament to express astonishment, indignation or rage at deaf couples wanting designer babies. This is a complete red herring which confuses and takes focus and attention away from the real issues.

It is possible to find deaf people who actively do want to have a deaf baby. But this is most often for cultural reasons rather than to perpetuate deafness as an empowering disabling state. Equally it's possible to find deaf people who are so shocked by that idea as to find it repugnant. It is probably somewhat easier to find people with a congenital impairment or condition who would welcome having a child who shared the impairment just as much and in just the same way as they would welcome, love and cherish a child who didn't.

And therein lies the real reason for the objections of deaf and other congenitally-disabled individuals and groups to one clause (14.4.9) in HFE. That clause states that when embryos are being selected for IVF, if there is a choice between those carrying the possibility of inherited impairment and those with no such possibility, the ones carrying no risk will always, automatically and incontrovertibly be preferred. What this represents in principle is a value judgement: an embryo

“What it represents in practice is nothing short of eugenics”

carrying the possibility of an impairment is always, automatically and incontrovertibly less desirable than one which doesn't. What it represents in practice is nothing short of eugenics, or at least the thin end of a eugenics wedge. It's clearly a move to engineer out congenital impairment. What it also represents is the abolition of choice.

contents

issue 6 April 2008



Sasha Hardway

The exciting young actress on her latest movie role, her soap hopes and why she hates hidden cameras

34-35

happening now

editorial.....3
Why deaf "designer babies" is not the issue

breaking news.....7-9
Access to Number 10, and the deaf embryo controversy

news round-up.....10-11
A new independent living strategy, more incapacity benefit reform controversy and Brent Martin's murderers are sentenced

campaigns.....13
Government figures lend weight to winter fuel campaign

politics.....15
Big hitters' welfare-to-work talking shop

mediawatch.....16
Is TV show a big break for disabled models, and Paul Merton's blind prejudice

disability rights.....19
Should we trade DLA for personal budgets?

world view.....20-21
A blind journalist's struggle to escape Norway's cotton-wool wrapping

one to watch.....23
Teenage confectioner Louis Barnett



comment now

letters.....36-37
Fuel poverty and government untruths, Tesco dragging its heels on bay abuse, and a parking attendant speaks out

andy rickell.....38
A call for disabled people to make new alliances

ask the experts.....40-41
Tricky questions answered on car tax exemption and where to find a PA for a foreign holiday

backchat.....42
Council plans for a media circus in a Somerset field and could America be about to elect its first social model President

guest column.....45
A former Lady Mayoress asks just how successful the DDA has been



your rights, your voice, your life



48-50

livingnow

homelessness.....25-28
Down and out and disabled

hate crime.....30-32
Who's committing hate crimes against disabled people and why sentences are lagging behind

Sasha Hardway.....34-35
The exciting young actress on her latest movie role, her soap hopes and why she hates hidden cameras

up close and personal.....47
Does language say who we are or what people think of us?

style.....48-50
Do spas need an access makeover?

local knowledge.....53
A group of young people on why their new book could help other disabled people find work

travel.....55-58
Argentina: more than just Pampas and Patagonia

tried and tested.....60
What do you do after analogue switch-off



25-28

MICHAEL PRESTON

road test.....62-63
Why the blue badge scheme needs radical change, and an exclusive look at Gowrings Mobility's new wheelchair-passenger vehicle

sport.....64-65
Funding crisis hits British Deaf sport and Dame Tanni heads a new doping review

entertainmentnow

arts.....66-67
Richard Butchins on his *Last Freak Show* documentary and Mat Fraser on an explicit book about sex

webwatch.....68
A great place to make friends and influence people

backlash.....71
Does Paul Carter have a carbon footprint

careersnow

worklife.....73

classifieds.....74-77

holidays.....77-82

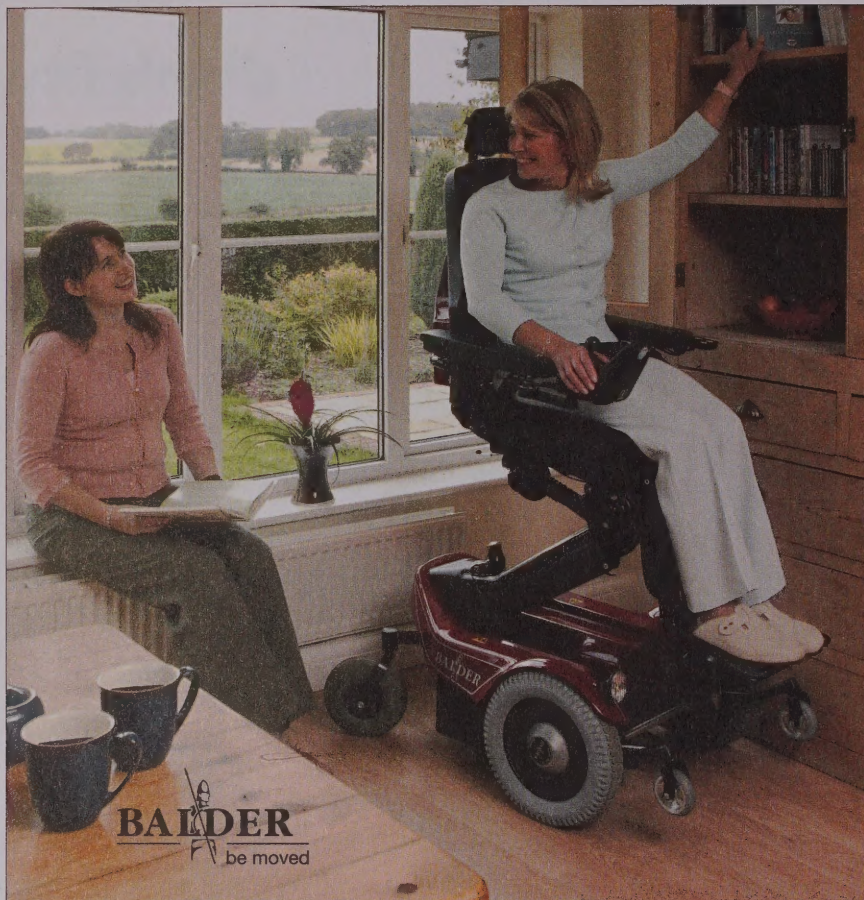
for sale.....70 and 78-79



19



55-58



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Living, learning, but no new laws

Katharine Quarmby

Jenny Morris is, clearly, quietly pleased with the independent living strategy, launched in early March.

No surprise: she has spent the best part of three years navigating the corridors of power as a consultant to the cross-departmental Office for Disability Issues, to help deliver the strategy for disabled people.

Co-production was at the heart of how it was developed – a departure from the usual tokenistic model of consultation, although Ms Morris smiles and says that everybody is “still learning”.

The regional workshops were problematic for disabled people because, she says, “it was quite difficult for people to recognise that they weren’t [just] being consulted. It was much more ‘here is a blank sheet of paper, what should we be doing?’”

Last summer, when she and others presented their interim report to ministers and a panel of experts, there was a “huge list” of more than 100 policy proposals. This was pruned to 51 in the final report.

Key to the report is an emphasis on older disabled

people and a move towards personalised budgets and direct payments, advocacy and brokerage, disabled parents and transition to adulthood.

The National Centre for Independent Living and the expert panel called for new laws, so I ask Ms Morris about the lack of new legislation in the strategy.

She opens up the report and points to the detailed monitoring framework. She adds that the government is considering setting up an independent living scrutiny group to oversee that process.

I ask if she is worried about the rumblings of concern from directors of social services and some academics about alleged

“We must change our attitudes to older people and apply the same aspirations to all disabled people”

fraud in direct payments – given that the strategy stresses that direct payments, coupled with personalised budgets, are the way forward. “It has been difficult in some organisations to change the



Jenny Morris: individual budgets could be the answer

culture and promote direct payments,” she says, adding that “there is some thinking that individual budgets will get over that”. So expect an intensification of choice and control – rather than any rolling back of that agenda.

The strategy focuses most strikingly on the rights of older disabled people. Dame Jane Campbell, Rachel Hurst and Jenny Morris herself are just three of the veteran activists who are passionate about this agenda. Ms Morris comments on the “unconscious ageism” permeating society, adding: “There has been a gradual realisation that we need to change our attitudes to older people and to apply the same

aspirations of full and equal citizenship to all disabled people, whoever they are.”

I ask, finally, how welfare reform and independent living should work together, citing the case of one of our readers who cannot get the social care she needs to iron a shirt, so can’t enter the labour market. Ms Morris replies that there needs to be more thought about how to “apply the personalisation principles that will transform social care to employment support and bring the two together...so the resources can enmesh to give you the choice and control so that you can get to work.”

• See News Roundup, pages 10-11

breakingnews

Deaf embryo row

Katharine Quarmby

A heated debate has ignited about whether deaf parents should be allowed to select an embryo that has a deafness gene. The row has gained extra momentum because of the human fertilisation and embryology bill, which is due to have its second reading in the Commons in the next few months. Clause 14/4/9 of the bill allows a hearing embryo to be selected, but not one carrying a gene associated with deafness.

This debate has divided the community. On one side is the British Deaf

Association (BDA), which is run by deaf people. The BDA states: "By codifying into law a preference for selecting embryos that are genetically associated with hearing, potential deaf people who would otherwise have been born will not have an opportunity to exist." Francis Murphy, the chair of BDA, adds: "This is a sensitive issue and we respect the parents right to choose but we want to make clear that Deaf embryos should be treated as equally viable as any hearing embryos."

Paula Garfield and her partner Tomato Lichy, who

are deaf parents, want to use IVF to help them choose a deaf embryo. Mr Lichy says: "If hearing people were to have the right to throw away a deaf embryo then we as deaf people should also have the right to throw away a hearing embryo."

The Royal National Institute for Deaf People (RNID), which isn't user-run, disagrees. Its chief executive, Jackie Ballard, says: "Decisions about which embryo to implant are for parents and their clinicians, but RNID does not support the selection of a deaf embryo for IVF implantation where a hearing embryo is

available." But she adds: "We will be working with MPs to ensure that no deaf parent feels under any pressure to have their embryos screened during IVF treatment."

Jamie Trounce (*Disability Now's* design and production editor), who is profoundly deaf, agrees with the RNID. In an email contribution to a discussion on BBC London's Vanessa Feltz show, he said: "I don't want to have a deaf child with my hearing girlfriend, but if my partner was deaf, I would still never choose to create a deaf child. It would be very unfair for the child. If the deaf child found out that its parents chose its deafness, they may feel devastated or resentful about it in the future."

Poor, cold and disabled

New government figures show for the first time how tens of thousands of younger disabled people are living in fuel poverty.

Energy minister Malcolm Wicks released the figures which showed that, in 2005, there were 98,000 English households with a disabled family member under 60 in fuel poverty.

The figures provide the strongest grounds yet for extending winter fuel payments to people under

60 who receive the middle and higher rates of disability living allowance (DLA).

They were released in response to a parliamentary question by Labour MP Roger Berry, who said: "These figures show that fuel poverty is a real problem for disabled people. This has now become a matter of real urgency."

But a Department for Work and Pensions spokesman said there were still no plans to extend the payments.

• See Campaigns, page 13



Michelle is one of the disabled people fronting a new campaign by the charity Changing Faces on London Underground to challenge public attitudes towards facial difference.

breakingnews

Ramping up the pressure

Elizabeth Choppin

Dame Tanni Grey-Thompson has thrown her weight behind a petition to make the front door of 10 Downing Street accessible for wheelchair-users.

The petition to Gordon Brown's office, fronted by disability access consultant David Burdus, has called for the government to address the fact that wheelchair-users cannot enter through the front door of Number 10 because it has a step.

Dame Tanni said: "I have signed the petition because I think Number 10 should be accessible. I have been there a couple of times and have been able to get in and out OK, but I think it would be a great message to send out if a building like this was ramped."

Mr Burdus first challenged the government on the issue in 1994 when he visited the then Prime Minister to receive an honour, but was forced to use a temporary ramp at the building's side door.

Mr Burdus said: "I think it gives a very bad impression of our government. It was shocking the way I was treated."

Andy Rickell, an executive director at Scope, said: "Wheelchair-users should be able to enter the front door of one of the most famous addresses in the world, which houses the centre of British political power, and not enabling them to do so sends out a very negative message to disabled people. It appears to suggest that their needs are not important and politically are



Temporary solution: Chris Brace (left), Sue Bott and Robert Droy (right) hand in a petition on independent living last year

a peripheral issue."

Disability campaigner Rachel Hurst said: "It's important for 10 Downing Street to be visibly accessible to disabled people. The fact that they're proposing to bring us in around the side reflects how they're dealing with us politically all the time, by

sidelining our issues."

A spokesman for Number 10 said the petition would be answered "in the usual way" following the closing date for signatures in August.

The petition had 139 signatures as *Disability Now* went to press. To sign the petition, go to <http://petitions.pm.gov.uk/Access10/>

Remploy legal threat

Elizabeth Choppin

The GMB union has vowed to launch legal action against the government and sheltered employment provider Remploy over lack of consultation on the company's factory closure plan as it moves more disabled employees into mainstream jobs.

The announcement in March followed the closure of the Remploy factory in York. By mid-April, 28 of the company's 83 factories will have shut or merged. Union officials say a further three factories in Wisbech, Poole and Manchester could now also close because more than 2,000 employees had taken the £5,000 voluntary

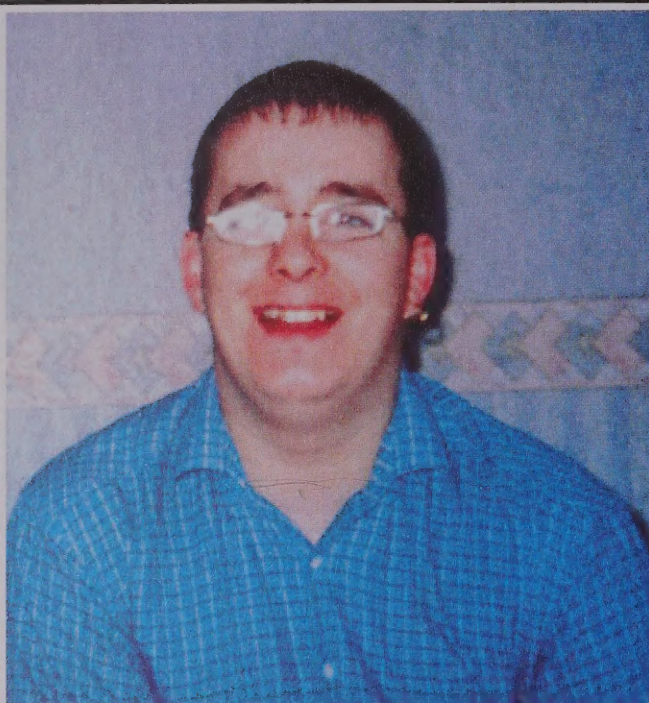
redundancy package.

Phil Davies, GMB national secretary for Remploy, said unions would pursue Remploy and the government in court but had been delayed while they helped disabled workers affected by the closures. He said: "Those people who thought closing factories was a good idea should come and see the devastation amongst some of these workers. It's been very traumatic."

He said there would be further protests in York this month and at Labour's autumn party conference.

A Remploy spokeswoman emphasised that the cost-savings of the closures would allow the company to quadruple the number of disabled people it helps place in mainstream employment.

A Department for Work and Pensions spokeswoman said legal action was a matter for Remploy.



Life sentences for young killers of Brent Martin

Three sadistic young killers who beat a disabled man to death were jailed for life.

Brent Martin (*above*) was punched, kicked, head-butted and stamped on during his ordeal last August on a Sunderland housing estate, Newcastle Crown Court heard.

Judge John Milford jailed ringleader William Hughes, 22, for a minimum of 22 years while Marcus Miller, 16, will serve at least 15 years, and Stephen Bonallie, 17, at least 18 years.

Hughes, from Washington Road, Sunderland, and Miller, from Baxter Road, had pleaded guilty to murder. Bonallie, from Birtley Ave, Sunderland, was convicted by a jury.

After the case, Julie Newman, chair of the United Kingdom's Disabled People's Council, said she was "disappointed" the judge had not pointed out that the crime was aggravated by hatred towards Mr Martin's impairment.

New strategy for independent living

The government launched a new independent living strategy to give disabled people more choice and control over the support they need and greater access to employment, transport, health and housing.

It included a review of local authority charges for care services, the piloting of individual budgets for disabled children and a review of how disability living and attendance allowances can better support independent living.

Six departments will work with user-led organisations to promote the strategy, with 12 such bodies getting £750,000 to promote independent living and be a role model for other areas.

Most adults now aware of DDA

Nearly three-quarters of adults are now aware of the Disability Discrimination Act (DDA), according to new figures.

The Office for National Statistics (ONS) said that around 75 per cent of non-disabled people were now aware of the act (as against 68 per cent of disabled people). This compared with 40 per cent of the general population in 1996, a year

after the act was passed.

The ONS also showed that around a quarter of disabled respondents still have problems using public transport while the proportion of disabled people with difficulties accessing goods and services dropped from 42 per cent in 1996 to 34 per cent by 2006.

• See Guest Column, page 45.

Tougher test coming

Plans to extend a tougher work test to all long-term claimants of incapacity benefit (IB) could force another 250,000 disabled people onto lower rates of benefit, campaigners said.

Disability Alliance (DA) accused the government of "fundamental dishonesty" over its Budget statement about long-term claimants of IB having to undergo the new assessments from 2010.

Campaigners said the change was simply an attempt to cut IB numbers.

The assessments had been due to be introduced for new claimants this October, alongside the new employment and support allowance (ESA), which will replace IB and disability-related income support.

A spokesperson for the Department for Work and Pensions denied any dishonesty in its approach.

Lords mourn peer



The death of a popular disabled peer raised new concerns about a shortage of specialist hospital beds for people with spinal cord injuries.

Baroness (Davina) Darcy de Knayth (left), who sat as an independent cross-bencher, died after The National Spinal Injuries Centre at Stoke Mandeville Hospital turned her away.

The Spinal Injuries Association said there were only 400 specialist beds across the UK, so that people with spinal cord injuries were frequently turned away.

Baroness Darcy de Knayth, who would have been 70 in July, was believed to have asked to be admitted to Stoke Mandeville when she became ill but was turned away and later admitted to Wexham Park Hospital in nearby Slough. She died two days later.

Baroness (Rosalie) Wilkins told the Lords that Baroness Darcy de Knayth was a "devoted" member and had helped to refine and pass every piece of disability legislation over the past three decades.

Higher standards for new social housing

All new homes are to be built to accessible "lifetime homes" standards within the next five years, according to a new government strategy.

From 2011, all new social housing will have to be built to the standards, with regulations introduced in 2013 if the private sector has not met "expectations".

The homes will have to incorporate some 16 design features or lifetime standards.

These include walk-in showers, wider doorways and staircases big

enough for stairlifts.

The strategy also includes a drive to promote "lifetime neighbourhoods", with guidelines on how developers and councils can improve access to public toilets, street lighting, information services, accessible parking bays and public transport.

There will also be a 30 per cent increase in funding for disabled facilities grants.

MPs call for action on veterans' health

Disabled veterans welcomed a report by MPs that called for more to be done for ex-service

personnel with mental health issues.

The Commons defence committee said serving service personnel receive adequate mental healthcare but identifying and treating veterans with mental health needs "relies as much on good intentions and good luck as on robust tracking and detailed understanding of their problems".

The National Gulf Veterans and Families Association called on the government to introduce a system in which veterans could be asked if they would like their medical records to be passed to the NHS.

Human rights report says efforts needed on health and abuse

The human rights of people with learning difficulties are too often ignored, according to the parliamentary joint committee on human rights.

The report said that the healthcare system still failed too many people and pointed to a worrying number of cases of abuse, neglect and hate crime.

It recommended action to promote awareness and a positive approach to the rights of adults with learning difficulties under the Disability Discrimination Act and the Human Rights Act.

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campaigns

Fuel figures aid campaign

The government has admitted that many disabled people are in fuel poverty. **Sunil Peck** reports

The government has admitted that there are nearly 100,000 disabled people under the age of 60 in fuel poverty.

The figures provide the strongest grounds yet for extending winter fuel payments to people under 60 who receive the middle and higher rates of disability living allowance (DLA).

They were released by energy minister Malcolm Wicks, in response to a parliamentary question by Labour MP Roger Berry, a long-standing campaigner for the extension of winter fuel payments.

The government has already said that in 2005, there were around 1.5 million fuel-poor households in England, of which more than 600,000 contained a disabled person.

But Mr Wicks has now admitted that around 98,000 of the households contained a disabled person under the age of 60, although he said it was impossible to identify how many of them claimed higher rates of DLA.

The figures are likely to have increased since 2005 because of sharp increases in fuel prices.

A household is fuel poor



JAMIE TROUNCE

if at least a tenth of its income is spent on heating.

Mr Berry said: "These figures show that fuel poverty is a real problem for disabled people. I recently raised this in the House of Commons again, calling for winter fuel payments to be extended to those on higher rate DLA. This has now become a matter of real urgency.

“The amount we receive simply does not afford us an acceptable quality of life”

"Any sane winter fuel allowance system would help compensate these people for the additional heating costs they incur," he added.

The government has vowed to eradicate fuel poverty among vulnerable groups by 2010, but a

Department for Work and Pensions (DWP) spokesman said there were still no plans to extend winter fuel payments.

He again issued the government's line that disabled people under 60 already receive benefits "in recognition of extra costs they may experience".

When pressed about the DWP's plans for helping fuel-poor disabled people, the spokesman said responsibility for fuel poverty was shared with the Department for Business, Enterprise and Regulatory Reform and the Department for Environment, Food and Rural Affairs.

But disabled student and *Disability Now* reader

Arlene Anne McKeever said the DWP's comments were "blatantly untrue".

She said many disabled people had no extra money to cover additional heating costs. "The amount we receive simply does not afford us an acceptable quality of life," she added.

Meanwhile, in his Budget speech, the Chancellor announced that winter fuel payments for the over-60s would increase from £200 to £250, while those for over-80s would rise from £300 to £400.

Paul Smith, executive director of the Spinal Injuries Association, said he was angry that the Budget did not extend the allowance to disabled people under 60 whose medical conditions required them to keep their homes warm.

And Steve Broach, campaign manager at Every Disabled Child Matters, said he was disappointed that it failed to extend the payments to families with disabled children.

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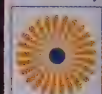
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E & OE

Old story, new Beginnings

Politicians, charities and job experts came together last month to discuss how to help more disabled people into work. **Elizabeth Choppin** reports

The minister for disabled people has told benefits and employment experts and a handful of disability organisations that the government's welfare reform plans are crucial for tackling the "blight of inactivity" in some incapacity benefit (IB) claimants.

Anne McGuire's comments – amid continuing concerns from disabled people about the government's welfare reform plans – came at a conference organised by the Unum Beginnings campaign to discuss the best ways to break down the barriers between disabled people and employment.

It took place just a day after the Chancellor announced in last month's Budget that all long-term IB claimants would from 2010 have to undergo the new work capability assessments (WCA) – veering away from previous statements that the WCA would only apply to new claimants.

Ms McGuire said the WCA would be introduced over three years from 2010 and that it was a necessary tool



to tackle "generational inactivity" and to help disabled people who wanted to work.

Liz Sayce (*above*), chief executive from Radar, called at the conference for far better joint working between employers and disabled people, saying that individuals should be more involved in negotiating solutions and "knowing what is possible".

She added: "Personalisation of services means you as employee knowing your own requirements, negotiating with your manager for adjustments, drawing on

individual budgets, Access to Work, the support of employment providers and health and social care – to suit your requirements."

Paul Jenkins, chief executive of mental health charity Rethink, said: "We agree with the general thrust of the plans but we're concerned that the right kind of support will not be available. What works for some disabled people might not work for

others, especially people with mental health issues."

Shadow disability spokesman Mark Harper MP told the conference that a Conservative welfare reform programme would mean a work assessment for all benefits claimants and a "payment by results" system for employment agencies.

Danny Alexander MP, shadow work and pensions secretary for the Liberal Democrats, called for one single working-age benefit, more involvement for voluntary and private sector organisations, and robust government support for claimants making a transition into work.

Mr Alexander said: "If claimants are expected to take responsibility, then government also has to take responsibility."

Rob MacKenzie, director of strategy and transformation for BT Business, said there was a very strong business case for employers to offer flexible working, which would, among other things, allow adjustments for disabled people, and so capitalise on an untapped pool of talent. He said seven out of 10 BT employees use flexible working.

→ Have your say

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mediawatch

Just a minute, Mr Merton

Maria Oshodi

For more than 40 years, *Just A Minute* has been a staple of Radio 4's panel game roster. In a recent edition, I was surprised and deeply offended to hear Paul Merton's repeated unhelpful and ill-informed comments about blindness. Asked to fill a minute on "What The Butler Saw", Clement Freud (above, right) had, quite innocuously, made a passing reference to "blind butlers", which Paul Merton (above,



left) then picked up and elaborated on in the most denigrating way. He presumed a blind family would not know what money they would be paying their butler and that he, Paul Merton, could pour soup over his blind butler's head and get away with it as the butler would think it was rain.

This poor attempt at humour, revealed a nasty, demeaning attitude towards blind people's abilities or perceived lack of them and went unchallenged by the programme's chair, who rewarded Merton by giving him extra points. There was also much laughter from the audience.

Distasteful and prejudiced jokes levelled at disabled people like this, should have been cut in the same way that I am sure jokes made about other minority

communities would be by a responsible producer. In the past, Paul Merton has acted as a PC monitor of himself and others on the subject of crossing the offensiveness barrier in humour, but it's a shame his detector failed this time.

Ultimately, it's counter-productive that while one Radio 4 programme like *In Touch* is attempting to address the increase of hate crime towards visually-impaired people, another of the station's programmes, *Just a Minute*, is allowed to freely demonstrate negative and damaging perceptions towards the same community.

Ground-breaking? Or car-crash TV?

Emma Bowler

A BBC Three series is causing quite a stir and it hasn't even been made yet.

Britain's Missing Top Model will pitch eight disabled women against each other in a battle for a prize of a fashion photo-shoot to be featured in a top women's glossy magazine.

Message boards are alive with comments such as, "missing – as in missing from BBC One?", fears over eligibility criteria, eg what's the lowest level of disability they'll accept: "a broken fingernail?", annoyance over



VisABLE model Shannon Murray

the 18-30 age restriction, as "it implies that anyone over 30 cannot be beautiful", and worries that the wide-ranging disability criteria could make the selection process "car crash TV".

The controller of BBC Three, Danny Cohen, says: "This series aims to challenge the artificial boundaries that

seem to exist in the beauty and fashion industries."

But Flash Bristow, a wheelchair-user, feels this is unlikely to really happen. "I'm a size 18. I know a disabled lady who's attractive, bubbly, gorgeous. Anyone who met her for the first time would agree. She's bigger than me. They are careful to not to say they want thin people but they don't make tank-sized versions of fashion clothes, do they?"

Billed as "ground-breaking", the idea of a disabled modelling competition isn't actually remotely new. Louise Dyson

at VisABLE People, the world's only agency uniquely representing disabled models, has organised three such competitions. "There are already disabled models out there doing the job, trailblazing, but this is a fashion competition and we get very little mainstream fashion work because it is a very exacting industry," she says.

It seems unlikely that a reality TV show is really going to make this exacting industry see the error of its ways in terms of its exclusion of disabled models, but we'll just have to wait and see exactly what effect the series will have when it goes out later in the year.

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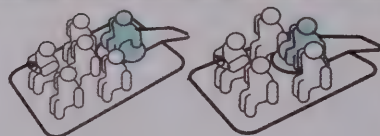
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The great DLA swindle



Jim Elder-Woodward warns that the government's social care reforms could mean that disability living allowance is not as safe as we think

Back in the early 1970s, I was driving around in one of those three-wheeler invalid tricycles: one of the few left on the road. I received a letter from the then government saying that if I handed back my tricycle I would be entitled to the new mobility allowance – FOR LIFE.

Now, some 35 years later, amid the hullabaloo of slogans being trumpeted by advocates of the new social care reforms, like individual “choice” and “control”, the Treasury is quietly trying to do away with the successor to my mobility allowance, the disability living allowance (DLA), and its

cousin, the attendance allowance (AA). The Treasury wants local authorities to be gatekeepers to DLA monies by including such resources in the disabled person's “personalised budget”.

A “personalised budget” is the money that a local authority sets aside to meet the social and personal needs of a disabled person. The person can then decide for themselves how that money is to be spent: by themselves to meet those needs, through a third-party care provider or on the local authority's own services. This means that people who hitherto shied away from

stigmatised social services and struggled to maintain their independence using their meagre DLA will now need to undergo a means-tested community care assessment.

Previous governments have said that the DLA was meant to refund the “extra cost” of disability – that's to say, help overcome the social barriers that impede disabled people's equal participation in society, such as the “extra costs” of transport, heating, laundry, shopping: the list goes on.

What's *not* on the list is social care. Yet increasingly, local authorities and even the Independent Living Fund itself have swindled this money from disabled people to underpin their under-resourced care budgets. It is

fair to say that many of those who are penalised for using care services by having their DLA taken from them fail to meet their increased living costs and consequently live a more impoverished lifestyle.

(This raises a question for those who, like myself, live under either the devolved governments of Wales or Scotland. In view of the Treasury's institutionalisation of the surreptitious local authority policy of using DLA for “care costs”, do Welsh and Scottish politicians and officials agree with this shift of policy and responsibility to the local level? And where is the accountability between the UK welfare benefit system and the devolved

Local authorities and even the ILF itself have swindled money from disabled people to underpin their care budgets

social care system?)

If every disabled person now has to undergo a debasing means-tested community care assessment to get what was previously and universally theirs by right of having a disability alone, more of us will experience a future of poverty and deprivation. So much for my 1970s naïve trust in the government.

worldview



PER EIDE/INNOVASION NORGE



A ticket to write

Journalist **Linn Martinussen** has had to fight the system in Norway to establish a career in journalism

The man behind the desk put down his pen and sighed.

"You're sure this is what you really want to do?" he asked.

"Yes," I said. "I've managed to get onto this university course in Edinburgh. It's meant to be the best journalism course in Britain and my ticket is booked, so I'm leaving in two days."

"And you're completely blind. How are you going

to manage by yourself over there?"

"I can only try," I replied. "I'm determined for this to work out."

"And you'll go even if you don't get our support?" he asked.

"Yes," I said. "I can't let this opportunity go."

When disabled teenagers graduate from high school in Norway, they meet someone from a job centre to discuss their future. This can often be a long, hard

process. In my case, I had to show that a blind person could do journalism and also live abroad.

In fact, I am only the second or third Norwegian blind person to study abroad.

The job centres pay for your university course if you're disabled so you don't have to worry about a student loan. After graduating, they find a work placement for you in the field you've been

studying in – on a contract but paid for by the job centre. Sometimes when the contract ends, the employer takes the disabled worker on and puts them on salary like its other staff, but more often disabled people find themselves having to go from workplace to workplace. Some even have to re-train, like a blind radio journalist I know who became a physiotherapist when his contract with a radio station ended.

The job centres prefer you to choose the course they think is best for you. I was advised to choose sociology or politics – good courses, probably, but not what I wanted to do.

A friend who has cerebral palsy wanted to study law. Unfortunately, her high school marks weren't good enough so she had to take a number of one-year courses to get the points she needed.

“Everything is a fight if you want to do anything that's different”

When she was finally accepted by a law school, the job centre refused to pay for her law studies but insisted that she continue with her previous studies instead. She's now taking

her case to court.

Although things are changing, the current system means that disabled people are effectively encouraged to stay on benefits and let their life be planned for them. Everything is a fight if you want to do anything that's different from what the job centres suggest.

My consultant back in Norway now has a lot of respect for me. When I went back and told him that I wanted to try my luck in London, he gave me a hug and wished me good luck.

My struggle isn't over yet. I do shift work in Dans le Noir, the restaurant in Clerkenwell, and pick up freelance journalism jobs where I can but I need either a steady freelance contract or a fixed-term contract before I can truly say I've made it.

It looks increasingly like I'll have to leave London in a few months – something I'm sad about, since my life's here now. Going back to Norway might not be such a bad thing but I'll have the feeling of having lost – and I want to succeed in London so I can encourage other disabled people who want to do the same as I did and follow their dreams.

Shocking images floor deputy

A Florida sheriff's deputy has been charged with abuse of a disabled person after being caught on camera tipping a quadriplegic man out of his wheelchair.

Video cameras had recorded Charlette Marshall-Jones tipping Brian Sterner onto the floor, after he refused to stand up to be searched following his arrest for a driving offence in Tampa.

The video footage shows Marshall-Jones searching Mr Sterner's pockets after he lands heavily on the floor.

Marshall-Jones also resigned from her job with the Sheriff's Office in the wake of the incident.

Truck driver back where he belongs

Five years after a crash broke his back, truck driver Scott Baldwin has become the first paraplegic person to be licensed to drive New Zealand's heaviest trucks.

Mr Baldwin set his heart on getting back behind the wheel of a big truck after the accident in 2003.

Following rehabilitation, he used a hand-control system installed with the help of compensation from the accident to win back his class five truck license.



Scandal sets up Paterson to make US history

Democrat David Paterson has become the USA's first blind state governor.

Mr Paterson, who was previously deputy-governor, took over as governor of New York last month in the wake of the resignation of Eliot Spitzer.

Mr Spitzer was forced to resign after details emerged of his apparent meetings with high-class call girls employed by an internet escort ring.

Mr Paterson, who has been blind since he was a baby, was considered a leading candidate to take Hilary Clinton's Senate seat if she becomes President.

Indian website could reach out to 60 million

The Indian government has launched a website that aims to reach out to the country's estimated 60 million disabled people.

The site – www.punarbhava.in – aims to make life easier for disabled people as well as carers, voluntary organisations and professionals.

Punarbhava, which means renewal or rehabilitation,

includes information on government policies, assistive devices, education and job opportunities, and a discussion forum.

It aims to consolidate all the information the government has on disabled people.

A national census found there were 22 million disabled people in India, just over two per cent of the population, but the true figure has been estimated as at least 60 million.

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Sweet sixteen

Sixteen-year-old confectioner Louis Barnett has dyslexia, dyspraxia, and his own chocolate factory in Shropshire. Louis started his business three years ago and now supplies major supermarket chains. He and his company Chokolit have already sparked the interest of TV crews from Japan and Russia.

What do you think is the best thing about being disabled?

Dyslexia and dyspraxia force me to look at things differently, forced me to look at careers outside academia and force me into opportunities I need to take.

What makes you angry?

People's perceptions of chocolate as fattening; good quality chocolate is healthy. Just avoid the stuff with vegetable oil on the label.

What's the funniest thing anyone's ever said to you about your impairment?

"You'll never make it."

How do you deal with people who barf on about your impairment? Have you any good putdowns?

You were wrong.

What's the one thing that could be invented to make your life as a disabled person better?

Spellcheck is already on computers; I'm quite happy about that.

What do you most like about being a confectioner?

Product testing.

And what do you not like about it?

Washing up.

Who's your favourite disabled person ever?

Richard Branson is dyslexic.



Candy man: Louis Barnett

Do you have any special or hidden talent apart from making chocolate?

Falconry since I was 11. I was having my hair cut and my barber told me he kept hawks. My parents bought me a falconry experience day and I ended up working at the falconry centre for two years. Now I have my own pet owl to fly and exercise.

If you didn't have your impairment, which other one would you like to have?

Memory loss. I'd like to live in the second, in the moment.

→ Who do you think is One to Watch?

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MICHAEL PRESTON

Down on the Streets

Being homeless is even tougher if you're also disabled. **Sunil Peck** investigates what is being done to help disabled people off the streets

Steve had been attacked by another homeless person a few days before I met him. He was punched and had his crutches kicked away in a dispute over £20.

Life on the streets is tough and Steve (*pictured, above*), who has thrombosis in his legs because he spent so many years injecting heroin into his groin, keeps himself to himself.

He is ten days into his second stint of living rough when I meet him and tells me he previously spent about two years on the streets. The pain in Steve's legs has been getting worse and he has no access to a nurse to bathe and dress his infected ulcers. He has no address so he cannot register with a GP.

Steve is always cold – even though he wears three coats. “I only spoke to

you so that you would buy me a cup of tea,” he says.

Some nights he dosses down among the bins behind the National Film Theatre on London's South Bank. On others he scales a ten-foot fence and climbs through a hostel window, where he crashes on his mate's floor.

“I want somewhere that I can call my home. Somewhere I can pay my electricity bill and council tax”

On Christmas Eve, he was admitted to a temporary hostel, usually the first step to permanent housing. After a few weeks, Steve expected to spend one or two years in what is known as a

permanent hostel while he waited for a flat to become available.

But there was one permanent hostel in London where he didn't want to stay because he had been bullied there, and this was the hostel they chose. He was given the choice of moving there or back onto the streets. He opted for the streets. He can appeal, but says the outcome will take months.

“I want somewhere that I can call my home,” he says. “Not a room in a hostel, but if I have to go that way to get one, I will. Somewhere I can pay my electricity bill and council tax.”

Nicholas Pleace, a senior research fellow at the Centre for Housing Policy, says it is difficult to know how many homeless disabled people there are.

People with significant sensory and mobility impairments are usually picked →

up by the NHS or social services, but he adds: "Certain aspects of homelessness might be a disabling process. There is a lot of depression in the homeless population – you have not got a house, or money, and you are alienated."

Duncan Shrubsole, director of policy and research at the homeless charity Crisis, believes that many disabled people do not get the help they need to avoid homelessness or escape it. "What is also clear, however, is that homeless people are disproportionately likely to have disability in the form of mental health problems. Around 30 to 50 per cent of single homeless people have mental health problems, including 12 to 26 per cent who have schizophrenia or other serious mental illness."

It is not only rough-sleepers who are defined as homeless. The term can apply to those in poor or overcrowded accommodation, who have nowhere to



MICHAEL PRESTON



MICHAEL PRESTON

site a boat or a caravan, or who are not rehoused by their council after leaving a psychiatric ward.

But a disabled person only qualifies for statutory help if they are both unintentionally homeless and in priority need, for example, because they are "vulnerable" due to their impairment.

The homeless charity Shelter says it is absolutely right that disabled people are seen as a priority. It is lobbying for an increase in investment in social housing to cut the number of people in temporary accommodation, which would help many disabled people.

Helen (pictured, above) is resigned to spending the rest of her life as a homeless person. She is 53.

She was in and out of hospital when she was younger, and has been in and out of hostels for most of her adult life, including about seven years on the streets.

She blames a housing association she says breached a tenancy agreement and "slung her out". She says all authorities are the same. "That's the way it is," she says.

Most of Helen's teeth are missing and her voice is nearly drowned out by the noise of traffic and pedestrians. She has been subjected to a lot of violence. She ended up in accident and emergency a few days before I met her. "I got beaten. I don't know what happened, I just woke up in hospital black and blue. If you accidentally bump into a person and you apologise to them, you just get insulted. They call you a slag, slut,

where, all sorts of things."

Helen uses crutches and has epilepsy. "How can housing associations say they help homeless people, and then throw someone like me who is epileptic and disabled out onto the street?" Then she answers her own question: "If people want to wreck your life, they will. You are just a black sheep; they don't have no respect for you."

Helen strikes up conversations with passers-by and sleeps on benches and

"She has been subjected to a lot of violence. She ended up in accident and emergency a few days before I met her. 'I got beaten. I don't know what happened, I just woke up in hospital black and blue'"

doorways at night; she likes McDonald's because of its warm air vents.

She talks in a matter-of-fact way about sleeping rough in the winter and being covered in snow. "I don't mind. It's not scary. It's a way of life," she says.

A Department of Communities and Local Government (DCLG) spokeswoman says the number of disabled people who qualify for statutory help has been falling since 2004.

In 2002, the government introduced laws that force authorities to provide suitable accommodation for "vulnerable" disabled people who are

unintentionally homeless: temporary accommodation must be provided until a long-term solution is found.

Since July 2003, all local housing authorities in England must have a strategy for tackling and preventing homelessness, including reducing homelessness amongst disabled people if this is a local issue. So far, the DCLG has given £300 million to local authorities to support homelessness prevention services, such as rent deposit schemes and mediation to resolve family and relationship breakdown.

In December, the government announced an extra £150 million in homelessness grants for councils and voluntary organisations over the next three years.

There is also the Supporting People

programme, which helps disabled and older people with support needs live independently, with £8.7billion since 2003.

John Callaway, manager of the Two Saints day centre in Southampton,

“It’s brilliant, because you have got support in the daytime. You have got hot water, toilets, a bit of food, phone calls”

says that if someone who has been homeless for some time does want a route out, there are good support services available, both in Southampton and other UK cities.

He says 80 or 90 people drop in to his centre for a meal or shower every day. A

significant number have impairments linked to drug or alcohol use, with 30 to 40 per cent of his clients having an impairment of some sort.

His staff can write referrals to hostels and offer assistance with benefit applications. There are also literacy and numeracy sessions and access to a GP and a community psychiatric nurse.

One of Callaway’s clients is Stuart, who tells me: “It’s brilliant, because you have got support in the daytime. You have got hot water, toilets, a bit of food, phone calls.”

Stuart spent 30 years living in sheds, caravans and hostels. He has depression and acquired a mobility impairment when he jumped off a falling ladder. Now 47, he is coming off heroin and says it is time for him to prove to friends and family he can



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hold down a flat and pay his own bills.

The centre's staff have helped Stuart find a permanent hostel. "When I had nothing, these people helped me out. If I had a million quid, I would donate it to help other people in my situation to get through," he says.

The government has certainly pumped millions into preventing disabled people becoming homeless, and figures suggest more homeless people are being rehoused. But what nobody knows is how many homeless disabled people do not apply for local authority support, or drift onto the streets because local authorities do not consider them vulnerable enough to rehouse.

If a disabled person does end up living rough, there are outreach workers, day centres and hostels that can point them



JAMIE TROUNCE

Ian, a *Big Issue* seller, is on the housing list. An ex-soldier, he spent several months on the streets after becoming homeless when the council failed to pay his rent

towards healthcare, mental health support, drug and alcohol services and permanent accommodation.

Investment in prevention and support is one thing, but how do you help the hardest-to-reach disabled people? Maybe in the same way that

prisoners become used to living behind bars, some homeless people become "institutionalised" by living on the streets. The question then becomes: how do you persuade people like Helen and Steve to take the help that society offers? ■

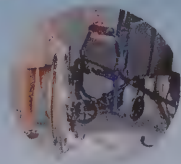
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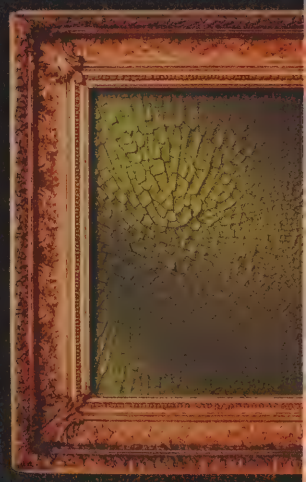


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Unequal before the law

Disability hate crimes mostly attract lighter sentences than others. **Katharine Quarmby** asks why

In 2005, Paul Taylor, 20, and Michael Barton, 17, were sentenced for murdering black teenager Antony Walker. They received sentences of 23 years and eight months and 17 years and eight months respectively. Mr Justice Leveson, handing down the sentence, said: "There is no difference between people of different races, each trying to live out their lives in peace. In spite of your youth, deterrent sentences are vital."

In June 2006 two men – Thomas Pickford, 26, and Scott Walker, 33 – were sentenced for the vicious homophobic murder of Jody Dobrowski. Their 28 year sentences were increased, under section 146 of the Criminal Justice Act, to reflect the way in which the killing was aggravated by homophobia. It was the first time that an aggravated sentence (because of evidence of homophobic bias) had been passed in a murder or manslaughter case. Judge Brian Barker said in court that the pair had only one intention when they went to the common: "homophobic thuggery".

The Sentencing Advisory Panel and the Sentencing Guidelines Council issue

advice to judges on length of sentence for all crimes. For murder, the middle starting point is 12 years and the lower starting point is eight-to-nine years. The higher starting point is 15-16 years where the victim is in a particularly vulnerable position or for murders involving gratuitous violence or sadism. The minimum term could be significantly higher for those involving several aggravating factors. Sentences

She called 999 and said that the man she had murdered was 'a little spastic' but the murder was not treated as motivated by disability hatred

for racially-aggravated murders automatically attract stiffer sentences. The Jody Dobrowski case is also seen as setting a precedent for stiffer sentences for homophobic murders. But when *Disability Now* analysed murders motivated by disability hatred, we found that those sentences were, on the whole, far lower. We looked at some prominent cases of so-called "racially-

aggravated" murder. In almost all cases, those responsible received sentences of above 20 years and a number above 25 years (see box, page 32). The judges also mentioned that race was a factor in the assault in every case. Such sentencing and comments give a clear sense of how the criminal justice system, quite rightly, views the gravity of racially-motivated crime.

We also looked at the sentences given to those responsible for the murder of eight disabled men: Rikki Judkins, Sean Miles, Steven Hoskin, Barrie-John Horrell, Colin Greenwood, Keith Philpott, Albert Adams and Brent Martin. In almost all cases, the sentences were far lower – and none of the cases was treated as motivated by disability hatred. Prosecutors did not call for disability hate to be mentioned as an aggravating factor in any of the attacks. The judges, therefore, did not mention it during sentencing.

In the case of Brent Martin, who was kicked, punched and beaten to death for a £5 bet, the ringleader, William Hughes, 22, was sentenced to at least 22 years and Marcus Miller, 16, and Stephen Bonallie, 17, received



Acting class: promotional material issued by the Crown Prosecution Service

sentences of 15 and 18 years respectively. But the judge did not refer to the crime as aggravated by hatred of Mr Martin's disability, which could have increased the sentences yet further.

Simon Unsworth, 20, and Aaron Singh, 17, who robbed and murdered Rikki Judkins, were given sentences of 18 years and 15 years respectively.

Edward Doyle, 34, Terry McMaster, 24, and Karen Feathers, 35, were given sentences of just 17, 15 and 14 years in jail. They had falsely accused Sean Miles of being a paedophile and had kidnapped him, stabbed him and then allowed him to drown.

Sarah Bullock, 17, and her boyfriend

Darren Stewart, 30, were jailed for 10 years and 25 years respectively for the murder of Steven Hoskin. Bullock had stamped on Mr Hoskins's hands, causing him to fall 100ft from a railway viaduct to his death.

Cousins Lee Davies, 28, and Brett Davies, 23, were ordered by Judge Christopher Pitchford to serve sentences of 18-and-a-half years and 17 years respectively for the murder of Barrie-John Horrell.

In the murder of Colin Greenwood, who was kicked to death, one 15-year-old and one 14-year-old were sentenced to a minimum of 12-and-a-half years for the murder.

In the case of Keith Philpott, who was falsely accused of being a paedophile, disembowelled and stabbed to death, Sean Swindon, 25, and Michael Peart, 22, had their sentences set at 20 and 15 years respectively. The Court of Appeal then raised their sentences to 28 years and 22 years respectively because of the sadism in the case – but not because of hate crime.

Disabled Londoner Albert Adams was murdered by Jennifer Henry. She stabbed him repeatedly. She also called 999 and said that she had murdered a man who tried to rape her, describing Mr Adams as "a little spastic". However, the murder was not treated as motivated by disability hatred. Henry was sentenced to just 14 years in jail.

Out of 17 murderers who carried out horrific attacks on eight disabled victims, just four were given sentences of over 20 years. By contrast, when we looked at five of the most horrific racist murders of the last few years, 10 out of the 13 responsible were sentenced to over 20 years (and five of them for 25 years or more).

Groups representing disabled people are concerned about our findings.

Julie Newman, who chairs the UK Disabled People's Council, says: "The matter of sentencing for those who are convicted of disability hate crime will be of concern as long as there continues to be a difference between this and other forms of hate crime."

Liz Sayce, chief executive of Radar, says: "These despicable crimes – up to and including murder – that are perpetrated against disabled people must be treated with exactly the same gravity as crimes motivated by racial or homophobic hatred. Only a consistent sentencing regime...will send that message."

Robin van den Hende, from Voice UK, adds: "If the criminal justice system is →



Sarah Bullock and Darren Stewart were jailed for murdering Steven Hoskin. Bullock had stamped on Mr Hoskins's hands, causing him to fall 100ft from a railway viaduct

to tackle disability hate crime then courts must increase sentences in all disability crimes and clearly state when a disability hate crime has occurred. We would be deeply worried if murders motivated by disability hatred did not lead to a longer sentence."

A spokesman for the Crown Prosecution Service said: "Sentencing is a matter for the judge in the case, not for the CPS, so we cannot comment on the sentence in specific cases. CPS lawyers can draw the judge's attention to any evidence of hostility to disabled people or to the victim's vulnerability but it is for the judge to decide on the sentence, based on the prosecution evidence and any mitigation by the defence."

So why are disability hate crimes treated differently from others? First, police, prosecutors and judges seem to understand racially-motivated (and, to a lesser extent, homophobic) attacks better than they understand disability attacks. Second, judges have been clearly instructed by the Sentencing Guidelines Council on how to treat racially-motivated attacks. Third, racially-motivated attacks, along with homophobic attacks, are more likely to be flagged as such by police officers and prosecutors, meaning that they attract media attention and a far higher sentence.

But there may be another reason – that disability hate crime differs from other sorts of hate crime and therefore may not be recognised as such.

We looked at the perpetrators of the disability-related murders listed above. In almost every case, the hate crime perpetrators were young, white and poor. Most were male. All of these markers are similar to other forms of hate crime.

But there is one striking difference. Those responsible for six out of the eight murders of disabled people were described as "friends" of those they murdered. (This also holds true in the case of Kevin Davies, who was held captive by "friends" and died in their care, as did Raymond Atherton.) Only two were stranger attacks. By contrast, the five racially-motivated murders that we looked at were carried out by strangers, as was the horrific, homophobic murder of Jody Dobrowski – a pattern that holds across other hate crimes.

This finding has implications for police and prosecutors. Liz Sayce says: "Hate crime must be clearly understood to include deliberate targeting of people who won't or can't fight back – even when the motive for the crime is exploitation (under the guise of friendship) rather than overt hatred. This is an educational issue for the police and prosecutors." ■

RACIALLY MOTIVATED MURDERS

KRISS DONALD

Murdered

Glasgow 2004

Imran Shahid, 29, Zeeshan Shahid, 28 and Mohammed Mushtaq, 27, were found guilty of racially motivated murder and sentenced to 25, 22 and 23 years respectively.

ANTHONY WALKER

Murdered

Liverpool 2005

Paul Taylor, 20, and Michael Barton, 17, received sentences of at least 24 years and at least 18 years respectively in December 2005.

ISIAH YOUNG-SAM

Murdered

Birmingham 2005

Waqar Ahmed, 26, Azhil Khan, 23 and Afzal Khan, 22, were sentenced to a minimum of 25 years each for racially motivated murder in May 2006.

LEE PHIPPS

Murdered

South Shields 2006

Scott Nicholas, 21, was sentenced to at least 22 years

MOHAMMED PERVAIZ

Murdered

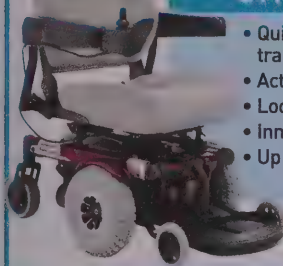
Huddersfield 2006

Christopher Murphy and Michael Hand, both 19, were ordered to serve at least 25 and 21 years for the racially aggravated murder. Graeme Slavin, 18, and Steven Utley, 17, were given 17 year minimum terms.



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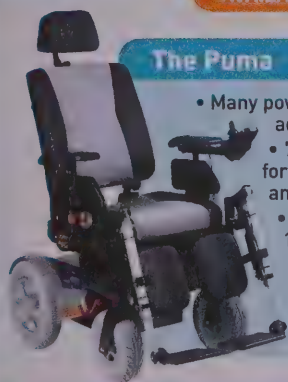
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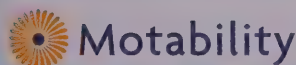


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Three years after landing a role in a high-profile TV drama, Sasha Hardway's career is finally taking off, she tells **Sunil Peck**

Sasha Hardway is waiting for a call to tell her if she has edged out another disabled actress and landed a part in a prime-time television soap opera. But she has been sworn to secrecy about which soap it is. She is trying not to build her hopes up, just in case she does not get the part. Then she laughs in a self-deprecating way, and adds: "But if I get it, they will have made the right decision."

Sasha is 21. The latest role in her three-year acting career was as Anais in the film *Special People*. The comedy, about a group of young disabled film-makers, headlined London's International Disability Film Festival in February and is due for general release this summer.

In the film, Anais is the love interest and is spurned by Dave (Jason Maza) because he does not want a girlfriend who uses a wheelchair. So, I wonder, has the character been influenced by Sasha's own experiences of love?

"I am not really someone who would go up and say 'I fancy you' in real life. I am not really that confident."

Sasha hadn't had the opportunity to hang out with other disabled young people before she met the cast of *Special People* on location in the Malvern Hills. There were only three or four other disabled people in her school; one of them was a pushy teacher. Sasha has now become close friends with the cast, and her experiences with them have been a revelation.

"When I met David Proud and Robyn Frampton, it made me realise how unimportant I am in terms of



Doing it the Hardway

wheeling myself around. I would never have wheeled myself up a massive hill a few years ago. I would always make sure that someone came out to the shop with me to give me a hand."

Sasha has performed from a young age. She danced before she lost the use of her legs, and sang at school. She joined VisABLE People, an agency for disabled actors and models, as a teenager and secured work as an extra and some modelling shoots. But she

was 18 when she landed her first major acting role, as Rachel in Stephen Poliakoff's television drama *Friends and Crocodiles*.

The experience made her lust for more roles. But when the offers dried up, she soon realised that she could not rely on acting as a career.

"I thought, 'Great, I have done a high profile film, I will get loads more work.' But I did not."

So she decided to study for a degree



SUNRISE MEDICAL

in graphic design which she is due to complete in June.

She did land a role in an ITV drama as a "bed-ridden tetraplegic", but her one line failed to make the final cut. She had auditioned for the main character, who was paralysed after a car accident, but lost out to a non-disabled actress. But Sasha does not believe the producers discriminated against her. "I think they wanted the actress to look similar to the real character. She had blonde hair and I don't."

Even if she misses out on the soap role, Sasha says the new character could still do a tremendous amount for disability equality; if the scriptwriters come up with strong storylines, the soap's non-disabled audience will start to see disability as a cool thing. If nothing else, Sasha hopes it will mean that nice guys have fewer qualms about approaching her in nightclubs.

"I always get the strange guys

coming up to me. Once I was in a nightclub and a guy came up to me and just grabbed my arms and started moving them to the song *Surfing USA*. I was so embarrassed. I felt like everybody was looking at me and I didn't really want to be a puppet. My friend reckons that all the nice guys are too shy to come up to me."

There were no disabled characters for Sasha to relate to as a young TV viewer. "I like the character in a wheelchair in *Balamory*, and I think if I was a young kid I would have looked up to her. I would have liked *Desperados* – about the wheelchair basketball team – too."

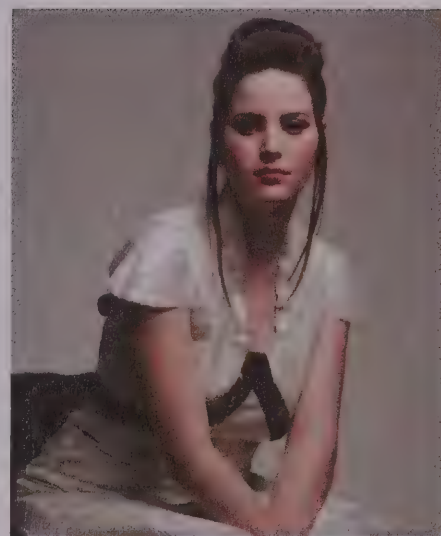
Sasha would consider playing most roles but says she would draw the line at appearing naked. She is not a fan of hidden camera Trigger Happy TV-style roles, either, where her disability could be used as a tool to embarrass unsuspecting members of the public.

"I went for one audition where I went up to someone on the street and I said, 'Have you seen my pusher?' It was supposed to be funny."

I thought, 'Great, I have done a high profile film, I will get loads more work.' But I did not

It will be a few years until there are any disabled actresses to rival Hollywood stars like Cameron Diaz, but she says scriptwriters and casting directors are slowly coming around to the idea of including more disabled actors. She believes that she would make a good role model for disabled youngsters, too.

"I want to be an actress, but I think that being a figurehead for disabled people comes with that, which I think is important. If there was to be a disabled person for people to look up to, it would be really cool if it was me." ■



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yourviews



LEO WILKINSON PHOTOGRAPHY

Government's 'untruths' over winter fuel payments

The comment made by the Department for Works and Pensions that "the benefits system already provides help for disabled people under 60 in recognition of extra costs" (*Disability Now February, Campaigns*) is blatantly untrue. In many instances, disabled people

in receipt of direct payments or individual budgets have to contribute at least £42 each week out of their disability living allowance towards the cost of their care. This leaves no extra money to cover additional heating costs. Those using direct payments are usually

severely disabled. Many have mobility and circulatory conditions and to live they must keep warm. Additionally, if people use an oxygen concentrator, the electricity their machine uses is supposed to be met by the Department of Health. However, as I myself have witnessed in 17 years, the amount paid has not risen, despite rocketing fuel prices. Disabled people who are reliant on their own wheelchair-accessible vehicle also have to pay for their fuel. The amount we receive simply does not afford us an acceptable quality of life.

Arlene Anne McKeever,
Northumbria University
disability studies PhD
student

Airline is miles ahead on toilet access

I am a permanent wheelchair-user, generally travel alone, and have for more years than I care to remember struggled with the fact that there have been no wheelchair-accessible toilet facilities on any airline. I have just travelled with Singapore Airlines four times and was assured that they had addressed wheelchair accessibility. True to their word, the toilets were

totally accessible, with a greatly improved aisle chair wheeled straight into the toilet. It is so easy. The airline staff were totally relaxed and supportive and nothing was too much trouble.

Singapore Airlines assure me they have similar provision on their planes in general. Spread the word and perhaps this will encourage other airlines to move forwards more quickly.

Mac McDougall,
via email

Room for improvement

I would like hotels chains to start recognising that as well as providing disabled rooms they should also take into account disabled family rooms. Whenever I try to book a disabled room with a bed for my daughter they cannot do this, saying there is not even enough room for a folding bed. How do we get hotel chains to recognise disabled families as well?

Debs Cannon, by email

Our carers should get bus passes too

I have a disabled bus pass which I am unable to use except on one route, which has a bus with a low-level entrance, or on the minibuses which cater for disabled people. I took my form to the town hall ready for a new pass and was told there would only be one pass for all over-60s. All disabled people who are unable to get onto standard buses should be issued with a pass giving free travel to the helper travelling with them. We should not be second-rate citizens. We are now getting access to buildings, hotels, etc, but not on all buses.

Mrs Bebington, Lancaster

We don't need labels to solve our problems

Disability hate crime is yet another tag to pin to a group of people already well labelled. There is no doubt that disabled people are attacked. However, is it really helpful to have another label?

The authorities create division by introducing labels. This is one of the main reasons society has so many problems: most people pass judgements based on labels.

Is this new label supposed to make disabled people feel any safer?

Stephen Bridge, Bury

Fining does work

I have probably got one of the most hated jobs in the UK. Yes, I am a parking attendant and I have just read with interest your articles on blue badge misuse (*Disability Now March*, *Blue badge blues* and *Road Test*). I have to agree that if you give out £60 fines you will cut the number of cars parking in disabled bays, as I have found out in my job as a parking attendant in a small town in the East Riding of Yorkshire, where we have been ticketing wrongly-parked cars in a small supermarket carpark for a number of years. As for the other supermarkets, surely if they are supplying the spaces they should do something about them being misused? Verbal warnings don't work most of the time, but a £60 fine sure does.

Stuart Harris, via email

Tesco should follow Halfords example

I have seen several reports in *Disability Now* but still nothing has changed at Tesco with its attitude towards abuse of disabled parking spaces. I was in Tesco and complained, but to no avail. There should be more companies like Halfords, where I complained about staff working on cars in the disabled bays: the manager was suspended, staff were severely reprimanded and a penalty enforcement notice has been put up. Also, I received £50 compensation. I spoke to an executive at Tesco head office, who told me a few pilot schemes are being tried, with CCTV/electronic surveillance and flying squads to impose fines on the offenders. I hope your readers will still complain bitterly to the big superstores and not take any excuses. Keep up the good work.

Trey, by email

System relies on medical model

I have just read your very interesting article on incapacity benefit (*Disability Now March*, *Breaking News*). I work for the Tribunals Service and am a Thalidomide-impaired woman of 45. The system needs a major overhaul. An

example: you get 15 points for not holding a pen properly [under the assessment process]. I have no thumbs so would immediately qualify! All disability benefits still rely far too heavily on medical-based evidence which, in these social model days, is completely ludicrous.

Ruth Daniells, by email



Aardman campaign was throwback to fifties

Change the way we think about disability? (*Disability Now* December 2007, *Breaking News*). How does Leonard Cheshire Disability hope to achieve this? By going back to the callipered, crutched, cripple collecting-box model of the fifties and sixties? Years of positive achievements by such individuals as Pistorius, Grey-Thompson and Blunkett, the Disability Discrimination Act and Mobilise members, all

forgotten in the negative, whining images presented by Aardman Animations, promoting disability as a condition deserving of pity and sympathy. I see the whole advertising campaign as a monumental waste of money that could have been better spent on exploring ways of further empowering disabled people and integrating all into a fair and just society.

**Sheila J Shutt,
Guisborough, Cleveland**

→ Have your say

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andy rickell



Retraining our allies

No one gives up power without a fight. That's why it's time to ease those who control disabled people out of the driving seat and into a new role, says **Andy Rickell**

Choice and control in your own life are joyous human experiences. But everyone, disabled and non-disabled, finds retaining choice and control a constant battle.

Disabled people find such choice and control more problematic than most. Indeed, society systematically denies disabled people the choice and control that non-disabled people enjoy.

Everyone learns to fight to keep what choice and control they have, including those people who have choice and control over disabled people's lives. Tricky!

This denial is itself disabling – hence the “social model” of disability, in which choice and control are given instead to others: parents, guardians, “carers”, service-providers, bureaucrats.

To experience equality, this choice and control must

be properly placed in the hands of disabled people, supported as necessary. Which means that those who currently have it must return it; and there's the rub. For, as I said, everyone learns to fight to keep what choice and control they have. This includes those people who have choice and control over disabled people's lives. Tricky!

If we are asked to give up power, our natural reaction is to justify why we should keep it. In the case of disabled people, arguments are manufactured around their inability to understand the issues, communicate or implement their choices, or their being too young or too old, or being too dependent on others' assistance or resources.

In particular, parents, who already realise that being a disabled child's parent is itself disempowering and disabling, might doubly fight for what little choice and control society gives them over their child's life.

We need to encourage this necessary power transfer with a new, positive way of thinking. The word “ally” best

summarises a new, positive role for people involved in disabled people's lives, where the parent, service-provider, professional, etc, supports the disabled person to maximise their choice and control and supports their

We need to support and train people committed to being 'allies' who can work in alliance with disabled people

putting their decisions into action. An “ally” is someone on your side, committed to your interests, who recognises and expands your autonomy.

Society, as I said, gives power over disabled people's lives to others, so it does not automatically encourage or reward people and bodies who want to be “allies”. It should. We need to systematically support and train people committed to

being “allies”, who can work in alliance with disabled people and disabled people's organisations.

One example of a body that does support “allies” is Parents for Inclusion. Scope is also working towards being an effective corporate “ally” of disabled people and their organisations. One success on this journey is the building of the Disability LIB (Listen Include Build) alliance of Scope and six disabled people's organisations (DPOs) which was awarded £4.2 million of Lottery funding for a capacity-building project for DPOs. The process of running this project, with Scope helping to lever DPOs into the driving seat, will provide a case study of how service-providers can be corporate “allies” to disabled people.

Contact me to find out more about being an “ally”.

• **Andy Rickell is an executive director at Scope: andy.rickell@scope.org.uk**

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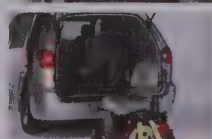
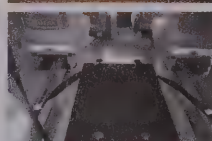
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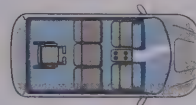
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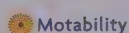
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Q Both my wife and I get higher rate mobility of disability living allowance, and we have a private car with tax exemption through my wife's mobility, but now I am getting a Motability car and we want to give our car to our son to drive for us. Can we leave the exempt tax on the car and register it in his name, or do we have to return the tax disc and DLA 404 (the exemption certificate) and start again?
Ron, by email

EP: As you know, if you receive the higher rate of the mobility component of disability living allowance (or the war pensioners mobility supplement), you can claim exemption from vehicle excise duty. The rules stipulate that you can only do this for one vehicle at a time and the vehicle must be registered in your name or in the name of someone you nominate to drive for you (the nominee). The vehicle

The vehicle must only be used for your purposes, for example shopping or getting prescriptions

must only be used for your purposes, for example shopping or getting prescriptions. If the vehicle is being used by the nominee or someone else for their own personal needs, then the exemption will be lost and the normal rate of vehicle excise duty must be paid. In your case, as both you and your wife receive the relevant benefit, you can gain exemption from vehicle excise duty for two vehicles. I note that the current exemption is obtained by your wife's entitlement. Therefore, you can receive your entitlement on your new Motability vehicle in the normal way and your wife can nominate your son to drive the old vehicle – as long as it is used only for her purposes. She will need to

ensure the vehicle is registered in your son's name and return the form DLA 404 (the exemption certificate) in order to have it altered to show the name of your son as her nominee. However, an advisor at the disability living allowance unit (DLAU) tells me that, as the vehicle use continues to meet the exempt criteria, he can continue to use the existing tax disc until it expires.

For further advice, contact the DLAU, tel: **0845 712 3456** or textphone: **0845 722 4433**.

Q I'm writing to you on behalf of a disabled friend who uses a wheelchair. My friend, Eve, would like to travel to America in three or four months' time, as this will almost certainly be the last opportunity she will have to see her elderly parents again. They live in the Bahamas, and are planning to make the journey to America one last time. Eve is not able to

visit them in the Bahamas, as the lack of wheelchair access makes it impossible. Eve has two carers, but neither is able to accompany her and I am not strong enough to lift her in and out of airplane seats. She has thought of advertising for someone to accompany her, but is wary of putting all her trust in a complete stranger. Can you think of any way she could be helped? Any advice or help you can offer would be very gratefully received.
Madeleine, by email

AW: Firstly, if Eve only requires assistance in order to be lifted in and out of her seat for her flight to America, then this facility will be provided by the airport staff, both in the UK and in the US, provided "special assistance" has been pre-booked with the airline. During the flight, should she wish to use the toilet, for example, while the airline staff would be happy to push her to the

toilet using a sky chair, a wheelchair designed for use in narrow gangways on aircraft, they would be limited in assisting her from her airline seat to the sky chair, for health and safety reasons.

Alternatively, Accessible Travel, in conjunction with Advantage Healthcare, can provide a travelling companion to assist Eve from her home and while on holiday. The in-flight and holiday packages are tailored to each client's needs by registered nurse

“They would be limited in assisting her from her airline seat to the sky chair, for health and safety reasons”

consultants. Following the initial enquiry, a local Advantage branch will arrange for their registered nurse consultant to visit the client in their home, discuss their needs, and undertake a care and risk assessment. We will then provide them with a package and price that matches their needs. For

further details, visit www.advantagehealthcare.com/accessibletravel.asp

As a guide, prices for two illustrative care packages are shown below. All start and finish times can be arranged with your member of staff. If you find you need more hours care than your package allows, you can arrange this with your carer and you will be invoiced at an hourly rate on your return. The client is responsible for meeting all travel costs for their nurse or carer, including travel tickets, accommodation, insurance and a minimum of £15 per day food allowance. The approximate cost of a package of six hours care per day from a carer for a one-week holiday is £1,070. For nursing care, the approximate cost of up to eight hours care per day is £1,520. All packages will depend on an assessment of the client.

Prices are based on clients outside central London. Prices are exempt from VAT and inclusive of employers' national insurance contributions.

RELATIONSHIPS

SIMON PARRITT

Simon is a chartered counselling psychologist who has also studied psychosexual therapy. He was the only disabled director of the former Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD).

FINANCE

DAVID CLARKE

David has spent 14 years in banking and has worked for three leading financial service providers. He is a senior partner with Clydesdale Bank.

PROPERTY

KATE SHEEHAN

Kate is a director of Better Living and an occupational therapist with 20 years' experience and a passionate interest in housing. Better Living works with manufacturers to meet the needs of the ageing population.

LEGAL & BENEFITS

LINDA CLARKE

Linda is director of Disability Law Service (DLS). DLS is the only service controlled and managed by disabled people that offers free legal advice to disabled people, families and carers.

EQUIPMENT

JOHN MANDRAK

John, who is blind, has worked for nearly 25 years as a disability journalist and consultant. He is an adviser on the Disabled Living Foundation's helpline.

TRAVEL

ANDY WRIGHT

Andy is a disabled travel industry professional with over 25 years' experience and is managing director of Accessible Travel, a specialist tour operator providing holidays for people with mobility impairments.

MOTORING

ED PASSANT

Ed is chief executive of the Forum of Mobility Centres. The centres provide driver and passenger assessment for disabled people across the UK.

MONEY, LEGAL & BENEFITS

ALAN BARTON

Alan is a social policy adviser for Citizens Advice, and an adviser at Rickmansworth Citizens Advice Bureau. He has a particular interest in benefits issues.

→ If you have a question for our panel

- phone us 020 7619 7323
- write to us Disability Now, 6 Market Road, London N7 9PW
- email us editor@disabilitynow.org.uk

backchat

Council erects tent for media circus



It's bad enough that Gillian

McCarthy has been forced to live in an unheated wooden shack in a Somerset field for the last 11 years, because the authorities have refused to build her a safe, chemical-free home.

Even worse that South Somerset District Council is now planning to evict McCarthy, who has multiple chemical sensitivity, and if necessary

dump her on the side of the road if she refuses to move to what she says is an inaccessible and dangerous mobile home.

But now McCarthy has had to cope with two council press officers sneaking onto the field where she lives to check out the best places to corral the media and set up TV cameras when the council comes to evict her.

The council has since apologised. But Backchat just hopes it isn't planning to set up a grandstand and sell tickets.

Barack's social model bandwagon



Is America about to elect a social model President?

Much as Backchat hates to jump aboard a bandwagon, Democrat Presidential hopeful Barack Obama's statement on his disability policies (easily found on YouTube) is well worth a view.

Obama talks about "a world free of unnecessary barriers" and says that attitudes must be shaped and buildings and

organisations designed to ensure access to education and independent living.

He promises that the US will again lead the world on disability rights and ratify the UN Convention on the Rights of Persons with Disabilities.

The former civil rights lawyer also pledges to end workplace discrimination, hire more disabled people as government employees and support "independent, community-based living for everyone who chooses it".

Fine words. But maybe, just maybe, he actually means them.



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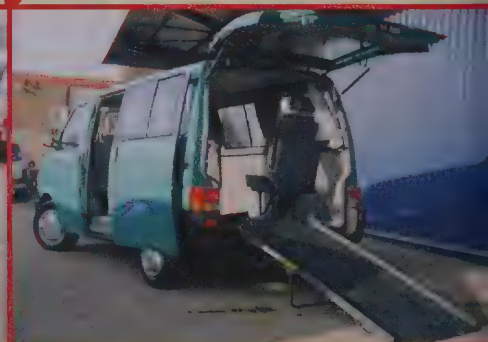


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guestcolumn



Act yet to take West End by storm

New government figures suggest the Disability Discrimination Act has improved access to goods and services. But **Pip Raymond-Cox**, former Lady Mayoress of Westminster, says there is still much more to do

Some ten years ago, I became Westminster City Council's first disabled Lady Mayoress – I am a permanent wheelchair-user – which gave me no power but a degree of influence. The Queen gave me an MBE for my work for physically disabled people and until 2004 my husband was Westminster's lead member on disability issues.

Today, wheelchair access in theatres and cinemas often remains inadequate. For example, the Haymarket cinema, in London's West End and owned by Cineworld, has no wheelchair facilities.

As Lady Mayoress, I told the John Lewis store in Oxford Street that one of their entrance doors was too heavy to be opened by anyone in a wheelchair, with a pram or buggy, or carrying big heavy parcels.

These have now been changed to doors that open automatically. But very heavy doors still exist widely in shops, banks, post offices and other public buildings – even inside Westminster Council House.

As Lady Mayoress, I had to tell the chief executive officer of Selfridges that counters were too high for someone in a wheelchair. The disabled lavatory was sited unhelpfully far from the entrance. And although Selfridges had put in disabled lifts, they had not adequately signposted their existence in the store.

Lack of adequate signage was widespread. At St Paul's Cathedral – in the City of London – I had to point this out to the Dean. It has now been corrected.

I also urged Westminster's

I have lost count of how many times people came up to me and said 'Lady Mayoress, I'm so sorry - I did not think'

many hotels to follow the example of the Mount Royal near Marble Arch, where six bedrooms were converted so that they had wooden floors, wide doors and lowered washbasins. These proved so popular and sent occupation rates up so



IAN BRITTON

Needed prompting: Selfridges in London's Oxford Street

significantly that the hotel has converted more rooms.

There are many dropped kerbs, but still not enough, and some, although dropped, still have too big a step.

Few hairdressers cope with people in wheelchairs, because their equipment is fixed, but it is possible to buy mobile wash-basins and dryers that can be moved to the wheelchair.

There is also a severe shortage of accessible parking spaces. Because some people use them illegally, we need more

spaces and much more rigorous enforcement. This shortage is especially marked near hospitals (eg St Mary's, Paddington).

I have lost count of how many times people came up to me and said: "Lady Mayoress, I'm so sorry – I did not think." And they continue to say such things to this day.

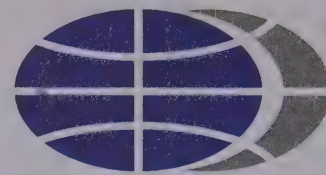
It is now over 10 years since the Disability Discrimination Act became law. We have come a long way since then but we clearly still have a long way to go.

→ Have your say

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- email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

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upclose & personal



Coming to terms

Disability language has always been a quagmire. **Betsy Valnes** asks if there's a way out

Personally, I'm flexible about the terms that people use about me – to a degree.

As long as those calling me a "crip" realise the necessity of inclusive education. As long as those calling me a "person with a disability" realise that I, too, deserve equal employment and career opportunities. As long as those calling me "disabled" know that I need health-care coverage that doesn't penalise me for having a brain tumour removed in my teens or selecting holistic medicine rather than the chemicals most doctors prescribe.

But when really thinking about terminology, I have to ask myself whether any of us is in a position to define right and wrong when it comes to disability. A range of language is used within our community: might accepting a variance in terminology itself be a form of diversity that

should be respected?

A few months ago, I participated in a publication focused on young people with disabilities.

Submissions came from parents, community members, medical professionals, siblings and friends. A few came from people with disabilities but most came from people without disabilities serving as "allies".

Although the essays were well meant, I was surprised by the negative referrals to disabled people as "deranged" and "one with a sterile future". While I thought myself to be flexible in the terminology department, I realised that everything has its limits. So, I had to write about it.

But I sat at my computer and watched resentment appear on my screen as I scolded these people who claimed to know so much about the disabilities about

which they wrote but, for the most part, had never experienced.

Granted, some words make me ill. If I heard them spoken, some words would force me to note the offence taken, while providing alternative, "socially appropriate" language in reply. But I am also posing the challenge, to myself as well, to look at the bigger picture: to bypass terminology and focus on larger goals. You can call me virtually anything you want, as long as your perception of me deems my insight to be valuable, my forethought to be worth listening to and my visions of change valid (and that may include updating terminology).

Vocabulary won't change

overnight. But the disability community (as well as our interaction with "allies") needs to look

past internal separations that stem from self-adhered name tags, and focus, instead, on larger platforms in our lives: education, employment and healthcare, to name just a few. Right now, we are missing opportunities to fuse people together because of first impressions

that come from as little as one-word phrases.

Admittedly, one of the simplest things in life is recognising that something needs to be changed and one of the most difficult things in life is actually changing it. In this particular case, my goal is to prioritise our quest to improve social justice rather than worrying so much about what we call those of us working to improve it.

deranged

disabled person

retard

handicapped

spastic

suffer

crip

→ Have your say

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Spas get a facelift

People are increasingly turning to spas in search of some rest and relaxation. We asked three disabled people to brave the steam rooms and bubbles at three top health clubs and resorts



CHAMPNEY'S TRING

Set in the middle of the Hertfordshire countryside, Champney's Tring is a dedicated health club and spa offering a wide variety of treatments, relaxation programmes and health breaks. It is pitched towards the premium end of the market.

Sitting at the end of a sprawling driveway, the resort is based in a stately home. The words "stately home" and "accessible" usually don't make the best of bedfellows but in Champney's Tring's case, things are different.

A recent £14-million refurbishment proves that buildings can be made accessible and yet retain their beauty and elegance.

I was initially surprised by the lack of specific accessible parking, despite there being "superior parking" closer to the entrance for premium guests, although in reality this wasn't much of an issue due to the number of available spaces.

There are ramps up to the grand entrance and into a large, wide reception area and the vast majority of the building is accessible to wheelchair-users and those with mobility issues.

There are still some steps to certain older areas, though there were portable ramps nearby, similar to the ones used at railway stations to get on and off trains. There was also a lift to reach the upper level.

The building's size does create a

problem. My room was almost at the end of the new garden wing and quite a walk from the main facilities, so popping back to collect a towel was a workout in itself. It would be best to query the location of the room when booking.

The pool is accessible through a level changing area with separate disabled changing facilities and plenty of seating at poolside level. There is no hoist to access the water (which I was informed about before arrival) but personally this didn't present too much of a problem as I tend to opt for the throw-myself-in approach.

A leaflet is provided on arrival with a detailed chart outlining which services are suitable (or not) for people with various conditions or impairments.

All the treatment rooms I looked at had fully adjustable treatment tables and were accessible by wheelchairs.

All the staff were extremely willing to offer help but most were happy to leave guests to relax until they asked for help.

The only time I needed to call for assistance was to lower the shower seat in my bathroom, although it turned out that it was down more to my incompetence at pulling a handle than a problem with the equipment.

All in all, my stay was very successful, though after a refurbishment on this scale, it certainly should have been.

Still, they should be applauded for managing to avoid the majority of the pitfalls and traps. Now if you'll excuse me, the jacuzzi is calling.

Paul Carter

THERMAE BATH SPA

The Thermae spa in the city of Bath offers a unique opportunity to bathe in naturally warm, mineral rich waters, just like the Celts and Romans did more than 2,000 years ago.

Bath's three natural springs rise to the surface at temperatures of at least 45 degrees celsius. They were first made use of by the Romans in AD 70, who built a sophisticated series of baths and a temple dedicated to their goddess, Sulis Minerva, to celebrate the water's therapeutic properties.

Today, a dramatic, contemporary, glass-and-stone building allows visitors the chance to enjoy the waters in a relaxing, airy and beautifully lit environment.

The facilities include two pools, steam rooms and an extensive treatment area, along with a cafe and restaurant. There is good wheelchair accessibility to all areas, with lift access to each floor and hydraulic lifts to lower you in and out of the pools. Trained lifeguards are on hand to operate the hydraulic lifts and can position them at the same level as your wheelchair. Toggle floats are also provided in the pools to offer support.

The large Minerva bath offers an



invigorating whirlpool, a massage jet and a gentle current to enable you to float lazily around the pool. On the top floor is an open-air rooftop pool where you can relax in the bubbles and warm water while enjoying stunning views over the city.

The steam room comprises four state-of-the-art glass cubicles, each infused with a different essential oil, and a central waterfall shower in which to cool off between sessions.

Treatments on offer include watsu, shiatsu massage in water, where you float in the private hot bath while a therapist gently stretches and manipulates your body. I took a fancy

to the dry flotation, where you relax on a warm cushion of water covered in mud, minerals and oils. The majority of the treatment rooms are accessible and all the treatment beds can be lowered. However, there are some instances where you will need to be able to step into a small shower cubicle to wash off therapeutic mud. A chair can be provided to sit on in the shower. When you book a treatment you will be asked to complete a form specifying any requirements or medical conditions.

The changing area has three large cubicles that can easily accommodate a wheelchair, and there are suitable





wheelchair toilet and shower facilities.

The Spa prefers clients to transfer from their own wheelchairs into a special manual chair if possible, but this chair has no rotating front wheels which made it very difficult for my carer to manoeuvre. The Spa is investigating more suitable alternatives.

Overall, with the good access and the unique opportunity to bathe in thermal waters, this spa is well worth a visit.

Kathy Longley

RAGDALE HALL

I have been a member of Ragdale Hall for many years. I recently became disabled after an accident and have since found the access very difficult. I wish to remain anonymous, so as not to compromise my membership.

General access to the main building is not too bad. There is level entry into the reception area and in some of the internal walk areas there are ramps so you can get round most of the parts.

Of the open areas, the coffee bar has large stone steps so there is no way you can get up there without assistance. I can get to the garden but find general access very limited.

In the pool, there is no hoist and there are steps with handrails down to

the swimming-pool itself. The training pool has four steps.

There is just one disabled toilet in the main building and one disabled changing area in the spa, but it is difficult to shower because the grate is too small and the floor area floods quickly. I also had difficulty adjusting the shower.

The disabled changing facility also has no lockers, so I usually leave my stuff in the disabled toilet and have to lock it with a coin. This has been known to be used by staff, though,

which makes me angry.

My biggest problem is with the new £3.5 million spa area. If you use a wheelchair, like me, it is not accessible at all. It features a new "candle pool" that is only accessible down seven spiral stairs. There is another pool area with 15 stairs.

At present, I can access the existing jacuzzi as it only involves a couple of small steps, but this will soon be coming out to make way for new changing facilities. The other jacuzzi has five steps up to it and then steps down.

Personally, I've never stayed overnight so I cannot say for sure what the rooms are like. Although there are none on the ground floor, there is a lift.

I am still able to walk a bit and can still get up and down a small amount of steps, but for anyone who uses a wheelchair permanently, or most of the time, like me, it is largely not accessible. ■

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Driven to succeed

Young disabled people have gone into print to prove that they and their peers can overcome barriers to work. **Elizabeth Choppin** reports



Nearly one in five people of working age in the UK is disabled but only half are in work. Poor access, negative stereotypes and lack of awareness or support are just a few of the barriers faced by disabled people seeking jobs. But a group from the Hertfordshire-based WorkABILITY project, which attempts to overcome work barriers for disabled people, has tried to dissect some of these issues in a new booklet, *User Driven*.

The 80-page booklet, aimed at employers and funded by the Local Network

Fund, tracked the first year of the group as its disabled students worked with local organisations and companies.

User Driven goes beyond a simple account of their work experiences and into their thoughts and feelings. It includes everything from practical recommendations for employers to poetry.

Most of the writing, coordination, design and editing was carried out by WorkABILITY members.

Mark Harris (*above, centre*), 18, from Weathampstead, edited, structured and project-managed the book. He says: "Hopefully the book will inform people about what

it's like to have a disability and will show that we're capable of working."

Katie Fraser (*above, left*), 32, from Welwyn, was a contributor. "Working on the book was brilliant. It was a great concept. Even though we only had five weeks to do it, we still met our deadline," she says. "The message we're sending is that disabled people are very much a part of society and

we can work just as much as other people can. The book says we're overcoming the barriers to work and we're going to fight to get disabled people into jobs."

Some of the obstacles to work identified in the booklet are to do with bad transport, ill-informed employers, poor information, shortage of adapted equipment, lack of confidence and low expectations from parents.

Andrew Bird (*pictured, right*), 23, from St Albans, wrote several articles for the book. "Although I have a severe physical disability," he says, "it doesn't affect my ability to think! I am really good at planning and organisation."

Andrew hopes *User Driven* will raise awareness of disabled people's potential: "I feel proud of the book because it shows the work that can be done by disabled people."

• Copies, at £4.99 plus £1 p&p, are available from Hertfordshire Personal Assistance Support Service. Contact the service via email at pass@hertspass.com or tel: 01707 321 442. Funds raised will go to WorkABILITY

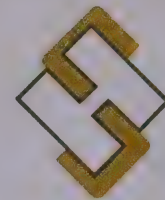
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Do you know of an innovative, small-scale, pilot project, ideally one run by disabled people themselves?

- write to us Disability Now, 6 Market Road, London N7 9PW
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Sussex Health Care



Rapkyns Care Centre, Broadbridge Heath, West Sussex

Beech Lodge, Broadbridge Heath, West Sussex

Norfolk Lodge, Horsham, West Sussex

Redwood House, Broadbridge Heath, West Sussex



Sussex Health Care is an award winning group of care homes that were founded in 1985. Sussex Health Care now operate 15 care homes, predominantly in the West Sussex area, providing nearly 450 beds, incorporating specialist care provision as well as care for older people. Sussex Health Care currently have vacancies in two of our care homes:



Rapkyns Care Centre opened 2 new bungalows in January 2007. The home is based in Broadbridge Heath and caters for young people with complex and multiple needs. The home is comprised of three bungalows for ten people and one for eleven which are purpose built and fully accessible for wheelchairs. Each single room provides en-suite facilities and track hoisting is available throughout. There is one bed available for respite care. There is a day centre on site with swimming pool and IT suite. Physiotherapy and hydrotherapy are available to service users as is 24 hour nursing care. A Speech and Language Therapist is also employed.

Beech Lodge is a purpose built bungalow which provides two wings of 10 bedrooms all with en-suite facilities providing care for young adults with multiple and complex needs. The registered care home with nursing has been equipped with all the latest technological aids and provides a safe, comfortable, homely environment for our service users. Person centred planning is at the forefront of our philosophy with the service user's needs and wishes at the centre of our service. Our philosophy is to provide the very best care in a safe and comfortable environment whilst respecting service user's rights to live as normal a life as possible.

Sussex Health Care also currently have residential vacancies in two of our care homes:

Both **Norfolk Lodge** and **Redwood House** have been skilfully converted to accommodate 8 people in each home and offer a specialised residential environment for adults with learning disabilities who may also present with moderately challenging behaviour.

Person centred planning is at the forefront of our philosophy with the service users needs and wishes at the centre of our service.

Our philosophy is to provide the very best care in a safe and comfortable environment whilst respecting service user's rights to live as normal a life as possible.

In 2008 the group are developing 2 new purpose built facilities

Beechcroft Care Centre, West Hoathly Road, East Grinstead.

This service will provide 2 purpose built 10 bedded bungalows with track hoisting throughout and en-suite facilities to all rooms for people with physical and learning disabilities. The home will also have its own hydrotherapy pool and a separate swimming pool.

Trained nurses, keyworkers and physiotherapists will be available over a 24 hour period. This service is due to open in May 2008.

Horncastle Care Centre, Plawhatch Lane, Sharpthorne, East Grinstead.

This service will provide a purpose built residential service with 24 hour nursing support for people with acquired brain injury and neurological conditions. This service is due to open in May 2008.

For further information

Please contact Corrine Wallace, Head of Specialist Care Services and Future Development,

Tel: (01403) 217338 • Fax: 01403 210424 • email: corrine.wallace@sussexhealthcare.org • web: www.sussexhealthcare.org



INVESTOR IN PEOPLE



Highway to heaven

Photographer and writer **Bizzie Frost** encountered glaciers, sealions and thousands of miles of open road as she and her family spent a month travelling through Argentina



In May 2007, our daughter Chania set off for Buenos Aires for a year, following a dream that had taken hold when she was 15 and fell in love with the country on a month-long Spanish language exchange.

Neither my husband nor I have ever visited South America and this was our golden opportunity.

On arrival at Buenos Aires, my wheelchair was brought up from the hold to the aircraft door (I have a spinal cord injury and can walk short distances with a walking stick. I travel with my own wheelchair).

I had found a cheap hotel/hostel on the net and we had booked a Ford EcoSport through RentaCar in Buenos Aires, although they do not have automatic cars for hire, and none with hand controls. However, www.rent-a-

“Neither my husband nor I have ever visited South America and this was our golden opportunity”

sol.com.ar has Toyota Corona and Honda Civic automatics.

Borges Design Hostel is not suitable for someone who cannot walk or manage stairs, but is clean and the beds are comfortable, and the staff are very friendly. Double rooms with air-conditioning are around £25, including breakfast.

We took a city tour coach and the last stop was La Boca, a poor area renowned for its brightly-painted wooden and corrugated-iron houses. The cobbled streets are an uncomfortable ride in a wheelchair, but I loved it.

The pavements around Buenos Aires are generally higgledy-piggledy with slabs missing and random areas that have been dug up. It would be extremely difficult to get around without help.

The next morning, we collected the car and headed down the RN3 towards Patagonia. Some people prefer to deal with the huge distances in Patagonia by flying, but this gives no idea of the immensity and emptiness of this beautiful area and we enjoyed watching the miles of completely flat landscape roll by, with cattle ranches and acres of sunflower plantations.

The next day, as we turned off the asphalt of the RN3, the unpaved and stoney “ripiro” road wound down a few gently rolling hills, welcoming us to the wide open spaces of the estancia of Bahia Bustamante.



Bahia Bustamante was originally set up in the 1950s by Lorenzo Soriano, a Spanish businessman manufacturing hair gel.

Four years ago, Matias Soriano, one of Lorenzo's grandsons, began developing his tourism business and converted derelict cottages into up-market guest houses, all with views over the deep blue water of the bay.

A visit to Bahia Bustamante is the ultimate escape from the hustle and bustle of modern living: there is no mobile phone signal, no local shop for your daily paper, almost no TV and no electricity during the day.

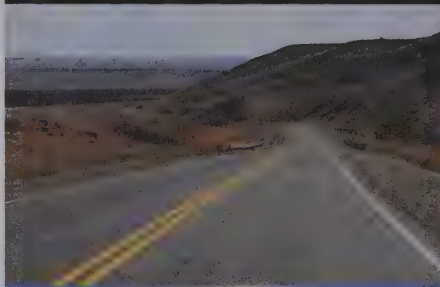
Chania had been working on the estancia as a volunteer guide, so the next morning she took us to explore an area of petrified forest where tree trunks dating back some 65 million years lie exposed and scattered among the sedimentary rock. She drove me as far as she could because the ground was too rough for me to walk on.

In the early evening, Matias took us all on a horse ride along the beach and across a peninsular covered with tufted grass that turned to gold in the evening sun. On another afternoon, we enjoyed a three-hour boat cruise to see the cormorant, Magellanic penguin, and sealion colonies. We must have spent at least an hour among 2,500 sealions and their flopping, frolicking, playing, growling, roaring and squealing young.

The rooms are not suitable for a full-time wheelchair-user, although they

Did you know?

The name Argentina comes from the Latin term "argentum", which means silver. The Spanish survivors of the shipwrecked expedition in the sixteenth century found indigenous people who gave them silver objects as gifts.



are planning to refurbish one of the large cottages, and are keen to make the accommodation as wheelchair-friendly as possible.

The desertification grew worse as we continued south, but even so we still saw the odd sheep or guanaco. Finding a decent loo en route became increasingly rare as we drove further south – at Piedra Buena there was a disabled loo, but it was totally trashed. You are unlikely to find loo paper, soap, or anything to dry your hands on.

We arrived at Isla Monte Leon in the early evening and received a warm welcome from Juan and Sylvia, who run their home as an up-market guest house. In the 1800s, the main house was imported in its entirety from the UK, down to the smallest details, such as door handles. The house is not designed or adapted for disabled guests, but the bedrooms and bathrooms are spacious and very comfortable.

Monte Leon used to be a sheep estancia but due to its miles of outstanding coastline with steep, rugged cliffs and colonies of sealions, penguins, cormorants and other wildlife, it was bought from Sylvia's family and has been turned into a National Park.

The following morning, we set off for El Calafate to see the renowned Perito Moreno glacier. El Calafate resembles a Swiss ski resort. Having your own vehicle is a huge benefit as you can arrive at the glacier before the crowds. The main bonus is arriving in time to see the early morning light move over the surrounding hills, creating rainbows above the glacier and gradually lighting up the huge jagged teeth of ice. No matter how many pictures you have seen of the glacier, it is still worth going to see it: it crunches, ➔

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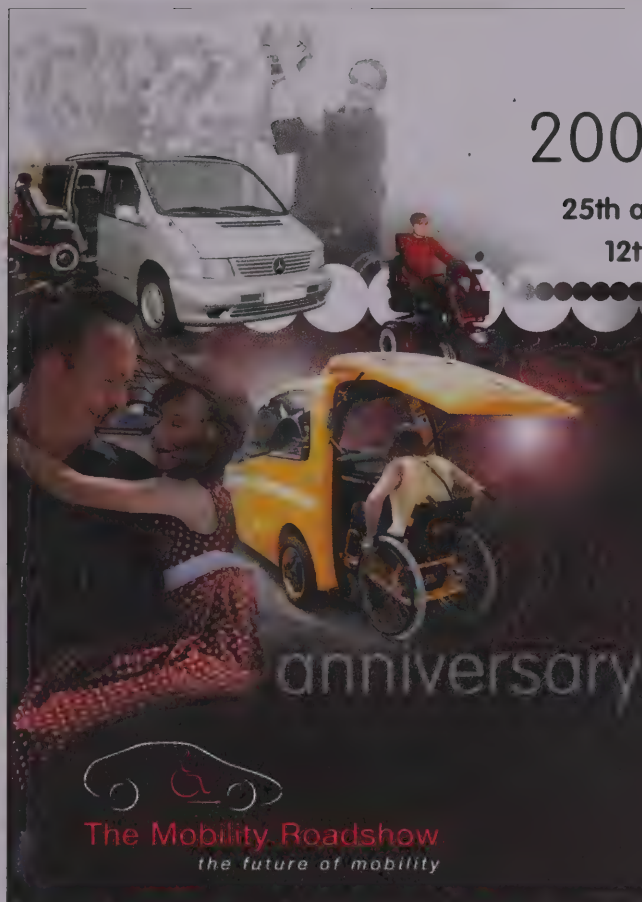
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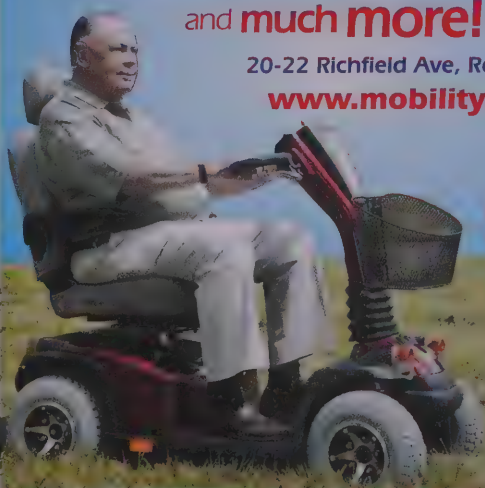
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Did you know?

Argentina has an area of almost 3.8 million square km – 2.8 million on the South American continent and the other million in Antarctica. It is 3,800km long and borders Uruguay, Brazil, Paraguay, Bolivia and Chile.

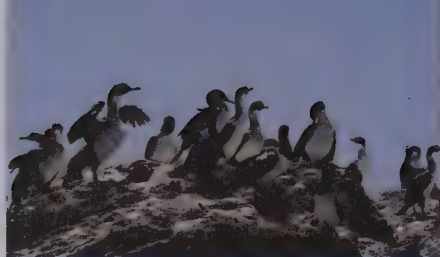
cracks, groans and creaks, and occasionally lets off loud retorts like gunfire, as it slowly melts and pieces break off into the surrounding lake, the tonnes of ice hitting the water with a resounding boom.

There are two boardwalks descending to about four different viewing platforms on different levels. Neither are suitable for wheelchairs, and only one suitable for walking sticks or crutches.

From El Calafate, our plan was to drive 3,300 kms up the western side of Patagonia to Mendoza, the wine-growing province. This route is Argentina's equivalent of the USA's legendary Route 66 and because a lot of it is "ripio" (gravel), and across desolate areas with very high winds, it can be a challenging drive.

Our stops included Estancia Los Toldos, about 820 kms from El Calafate, a ranch which includes the 9,000 year-old rock paintings of Cueva de las Manos Pintadas (Cave of the Painted Hands) and Los Antiguos, a fruit-growing town renowned for its cherries on Lake Buenos Aires on the Chilean border. It was wonderful to wake up at dawn and look out of a huge picture window and see the sun rising over the lake.

After driving 1,000 kms, we arrived at Esquel, where we took a ride on La Trochita, the Old Patagonian Express. It is a steam train that runs on a narrow 75 cm track to Nahuel Pan, 22 kms away. Its narrow carriages with their wooden benches (cushioned in first



class) are pulled by a smoke-belching steam engine through the scenic hills of the Estancia Leleque.

By 1 March, we had driven 5,956 kms. Our final destination on the RN40 – the "Cuarenta" – was Mendoza, 1,450 kms away.

On the drive down the Atuel Canyon, we passed a blond girl sitting in a chair with a sign advertising whitewater rafting. It was a very gentle run, but we all got soaked.

When we reached Mendoza, the opening of the annual Wine Festival was being held in the Plaza Italia. The descendants of the Italian immigrants celebrate their background and there was a line-up of opera singers to entertain the crowd. Like Buenos Aires, Mendoza is not easy to get around in a wheelchair. They have attempted to make ramps onto the pavements but many of them are badly broken-up and pavements are steep. However, there was an article in the local paper saying that all buses in the area were to be made "wheelchair-friendly".

The next day, we drove the 1,060 kms to Buenos Aires non-stop. The highlight of our last few days in Argentina was a football match at La Boca Stadium,

where we watched the Boca Juniors play Atlas from Mexico. The match wasn't that special, but watching the Boca Junior supporters was: the stadium is renowned for its shaking, caused by the supporters jumping up and down in unison when they get excited.

After the match, we found a huge guitar-jamming bar in the Palermo district, right beside the Borges Design Hostel where we were staying. The bar provides guitars, and anyone can go in and use one. It was a great way to end our stay, to hear the joyous singing of local folk songs continuing well into the night. We left at 3 am.

Argentina is a beautiful country, with warm-hearted, friendly people and there are lots of interesting and adventurous things to do. If I was completely wheelchair-dependent, I would plan my trip through a travel agent who could assure me that the hotels have the right facilities. I don't think I would travel by road, because of the distances and en-route facilities – I would fly instead and select several really special destinations: El Calafate, Mendoza, Bariloche and the Seven Lakes Route, the Iguazu Falls in the north (which we didn't see), and Buenos Aires. A short course in Spanish could be useful. Argentina has its heart in the right place when it comes to people with disabilities but in practical terms, it has a long way to go. I loved every minute. ■

• Read Bizzie's blogs from Argentina at www.disabilitynow.org.uk

• Bahia Bustamante details: www.bahiabustamante.com
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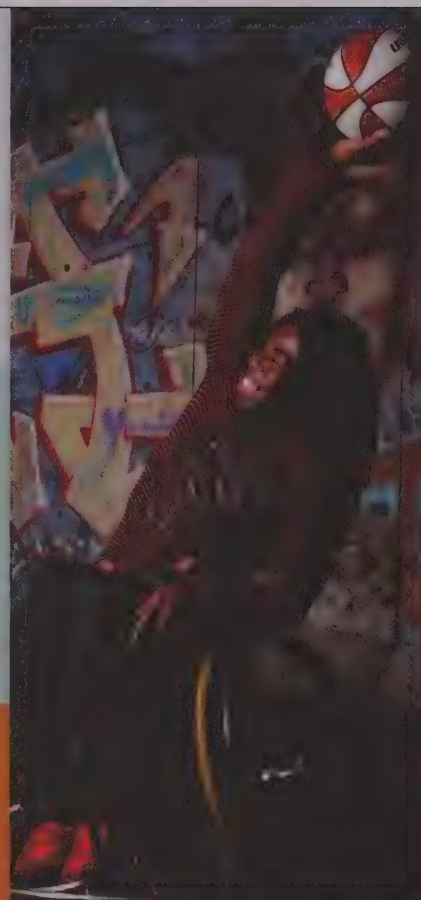
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Analogue switch-off, digital choices

Between now and 2012 we'll all have to go digital with our televisions. **Ian Macrae** asks what choices are available to us once analogue switch-off happens

It may sound like your worst nightmare. You go to bed one night after cocoa and the epilogue, you wake up the next day, your telly doesn't work any more. But of course, in these days of 24/7 channels, rolling news and wider choice it won't be like that. In reality, saying goodbye to analogue should mean waking up to a bright new digital dawn. It also doesn't mean that your trusty old analogue set will no longer work, it just needs to be made capable of receiving the new digital services. As with many things, the secret is in being prepared.

Analogue switch-off isn't just about more choice of channels though there are lots more of those. You can also choose how you receive the digital services and how much you want to pay.

The cheapest long-term option is Freeview. You make a one-off purchase of a set-top box which plugs into your existing TV and gives you access to up to 35 "Free-To-Air" TV channels, including the mainstream ones from the

BBC, ITV, Channel 4 and 5, plus a large number of radio stations, some of them only available digitally. You can buy a Freeview box for under £20 from your local supermarket, though more sophisticated and expensive versions are also available. And that's it. No frills, no monthly subscriptions. Receiving Freeview does rely on having a good aerial and you may need to upgrade your existing one.

Another option is to have your service delivered by cable from Virgin Media. Here, and with the satellite option from Sky, the number of channels will depend on which of their

packages you opt for, which will also determine how much you pay each month.

An additional incentive for taking the Freeview option may be the help scheme, set up and run by the BBC, which was given responsibility for rolling out the whole digital switchover programme. Under this scheme, many elderly and disabled people are offered provision and installation of a selected Freeview box at a fixed, one-off rate of £40. If you qualify for the scheme and are also on low income signified by particular benefits, you may be entitled to the box and installation free. The scheme has not

plumbed exclusively for one particular set-top box.

Instead it has drawn up a list of required functions which include audio description and subtitling available at the touch of a button.

In the next issue, we'll take a closer look at how the switch-over worked in reality for disabled people in Whitehaven and look ahead to how things go in the Scottish Borders, the next region to go totally digital.

• **More info on Digital Switchover at** www.digitaluk.org
• **Help Scheme fact sheet at** www.disabilitynow.org.uk





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Blue is the colour

Just about every car on the road seems to be using a blue badge these days. Now, 37 years after the original scheme was launched, **Helen Smith** says it's time for an overhaul

The orange badge scheme was first established in 1971 to provide a range of parking concessions for disabled people.

Since then there have been enormous social, political and environmental changes (not to mention the badge turning blue), so it's hardly surprising that 37 years later the scheme is in tatters. In response, the government is consulting on a comprehensive blue badge reform strategy that looks at eligibility, concessions and administration, but is it too little, too late?

The number of badges has soared to a whopping 2.3 million. Are there really 2.3 million severely disabled people in England?

In my view, the current scheme has failed and there's an urgent need for radical change. For a start, I can't remember the last time I was actually able to use my



PAUL CARTER

Booked: A national database would help wardens issue fines

blue badge. Last time I went to the supermarket, every disabled bay was full, so I went home and shopped online. When I went to hospital, I ended up having to be dropped off and picked up as there was nowhere to park. And I don't even bother driving to the city centre as the chances of finding a space are so low.

The number of badges has soared over the last 20 years. In 1987, 673,000 badges were on issue in England, but by 1996 this had risen to 1,517,000 and by 2007 it had risen again

to a whopping 2.3 million. This figure is still growing by four to six per cent a year. Although we have a growing population of older people, are there really 2.3 million severely disabled people in England?

Even if the new reform strategy tackles eligibility, who will make sure all the respective councils adhere to the new guidelines?

And even if changes were brought in tomorrow, it would still be three years before all the current badges expired.

Couple this with the large

number of badges, used by non-disabled people, that have been stolen, forged or "borrowed" and you end up with the blue badge disaster we are currently seeing.

The scheme needs radical reform to restore its reputation and credibility. To bring improper use to an end, I propose assessing – in the next six months – every current holder, as they do in some other European countries, and also making sure every new applicant is assessed and meets the criteria. I'd also introduce a national database so traffic wardens can tell instantly if a badge has been reported stolen or the holder has died. This would require investment but if this scheme is to benefit disabled people for another 37 years it is time drastic action was taken.

• The closing date for the DfT's consultation process is 17 April: www.dft.gov.uk/consultations. To respond, contact Ella Roberts, tel: 020 7944 4780, fax: 020 7944 6102 or email: bluebadgeconsultation@dft.gsi.gov.uk



JAMIE TROUNCE

A Fiat of engineering

Gowrings's new Doblo conversion is at the top of its game, says **Paul Carter**

This month, we have been given an exclusive look at the new Gowrings Mobility Fiat Doblo wheelchair passenger vehicle (WPV) conversion.

It is the first time Gowrings has converted a Fiat since the Fiorino in the 90s and the company regards this as one of its best-designed WPVs. So how does it measure up and is Gowrings's optimism well-placed?

Access by wheelchair is via the rear and the Gowrings Doblo comes with a tailgate rather than double doors, which as well as making the vehicle less "van-like", also acts as a rain cover in the inclement British weather.

A fold-out ramp with supporting gas struts was relatively easy to open out and provided straightforward access to the interior.

Hydraulic suspension is available as an optional (paid-for) extra to lower the vehicle further, if required. A winch can also be fitted if passengers find it hard to get the chair up the ramp.

Internally, the Doblo

comes alive with space. The rear Fiat seats have been removed and replaced with custom ones fitted to the maximum width to allow more space.

The floor is lowered so the passenger is at a similar

height to seated passengers and does not have his or her head pressing against the roof.

One special feature on the conversion is a storage pack that incorporates a small lockable unit, a larger boxed area for shopping bags and a smaller netted area.

Up front, the Doblo won't win awards for its beauty. This is possibly an unfair criticism, though, as it is unlikely that many people will be drawn to the Doblo for the quality of its dash.

Equally, drive-wise, it fails to set the heart racing on account of its performance; perhaps more importantly, it provided a very smooth ride quality and more than adequate pull.

All in all, the Fiat Doblo lacks the subtlety and finesse of vehicles at the premium end of the market such as the Chrysler Voyager but for those wanting a spacious, comfortable and well-considered WPV without breaking the bank, this is a car at the top of its game.



The Doblo Dynamic featured relates to the 1.4 petrol, available from 1 April 2008 at no advance payment on the Motability Scheme. The One Touch Extra Low hydraulic lowering suspension is available for an additional £895.

sportnow

by Paul Carter

UK Deaf Sport in funding crisis



DOUGLAS C. PIZAC/AP/PA PHOTOS

Waving the red flag: Deaf athletes could find it too pricey to attend the Deaflympics in 2009

The chair of the governing body of deaf sport in the UK has criticised the government for a "lack of support and recognition", claiming that funding priorities have been focused on the Olympics and Paralympics.

Craig Crowley, the chair of UK Deaf Sport, said he understood that the organisation's government funding from UK Sport of £42,000 per year would expire on 31 March, as *Disability Now* went to press.

He added that this would mean UKDS had no choice

but to consider not sending a GB team to take part in the Deaflympics (formerly the World Games for the Deaf) in Taipei in 2009 as many athletes would be unlikely to be able to afford the £3,000 cost per person estimated by the GB Deaflympic Organising Committee (GBDOC).

In a letter to sports minister Gerry Sutcliffe, Mr Crowley said that "UKDS now appears to be facing a situation whereby your department [the Department for Culture, Media and Sport (DCMS)], UK Sport and the home country sport

councils are all avoiding any responsibility for our elite deaf athletes who choose to participate in the Deaflympics rather than the Olympics or Paralympics."

He told *Disability Now* that the attitudes and actions of the DCMS and UK Sport towards deaf sport were "grossly unfair and unacceptable", given that UKDS had followed their "strategic modernisation guidelines" for the last five years.

He added that he was convinced they had "discriminated against deaf athletes' equality of

opportunity to succeed in their sporting fields".

In his response, sports minister Gerry Sutcliffe said that the "difficult decision" taken by UK Sport had come from a need to focus on support for elite Olympic and Paralympic athletes in the lead-up to Beijing 2008 and London 2012.

Mr Sutcliffe said he "fully understands" concerns about the impact on the long-term development of British deaf athletes.

He added: "I recognise it is important that they are given the opportunity to compete at the Taipei Deaflympics in September 2009 and I remain optimistic that they can obtain the necessary funding in the 19-month period leading up to that date."

He said UKDS should contact the English Federation of Disability Sport (EFDS) for further advice on funding options.

"I would again like to praise the good work of UK Deaf Sport in providing opportunities for deaf people to participate and helping to find future deaf athletes of tomorrow; including those already on UK Sport's World Class Pathway," he said.

Dame Tanni to head doping review

Dame Tanni Grey-Thompson has been appointed by UK Athletics (UKA) to lead a review into the organisation's anti-doping policy.

The former Paralympian will chair the review, set up

following Dwain Chambers's selection for the World Indoor Championships, even though he had previously tested positive for a banned substance.

Dame Tanni said she was still working on the review's terms of reference but would consider "every available

option" including "extended or lifetime bans from representing Great Britain".

"My mandate is clear and I believe the time is right for UKA to play a leading role in driving change to ensure that drug offenders cannot walk back into our sport unchallenged and untested."

Niels de Vos, UKA chief executive, said: "I am delighted that Tanni has agreed to chair our review panel. She has the respect of the global sporting community and will ensure the review delivers well thought-out and robust solutions."

Q&A: Sarah Storey

In our fourth Paralympics profile in the run-up to Beijing, we put questions to the UK's swimmer-turned-cyclist Sarah Storey (née Bailey)

What first got you into disability sport?

I went to a regional swimming competition in 1991 and from there was selected for the Barcelona Paralympics in 1992.

What is your biggest sporting achievement so far?

Double gold on my international debut in Barcelona in 1992, triple gold in 1996 and five gold medals in 2005 on my international debut at the cycling Europeans.

What is your biggest sport disappointment so far?

Failing to get a gold medal at the 1998 world champs.

What are your ambitions for Beijing and beyond?

To win a cycling gold in

Beijing and then continue to compete for the London Games in 2012.

Who are your sporting heroes?

I was mesmerised by the 1984 Olympics in LA and loved watching the likes of Daley Thompson, Steve Cram, Seb Coe and Sarah Hardcastle. In 1992, prior to my own international debut, it was the gold medals of Linford Christie, Sally Gunnell and Kristina Egerzegi who inspired me to win my own.

Do you think the GB team is in good shape for the Beijing Games, and beyond that, London?

In cycling we are in great shape, so much so [that] we may end up leaving some current world champs at



JOHN WALTON/EMPICS SPORT/PA PHOTOS

Sarah Storey: gold medallist in the 500m time trial at the VISA Paralympic World Cup in Manchester last year

home because we don't have enough places.

Who is your tip to be the next star of GB Paralympic sport?

Lizzie Simpink (swimmer) is already a star and not quite 14!

What are your interests away from the world of sport?

None really! I go to watch Manchester United in my spare time and apart from that I love travelling and spending time with family and friends.

artsreview

FILMING THE FREAK SHOW

Filmmaker Richard Butchins tells **Kelly Mullan** why BAFTA snubbed his new documentary

Ebullient documentary-maker Richard Butchins (pictured) gets his subjects to relax by making them laugh and sending up his disability – a left arm paralysed by polio – with tall tales of botched attempts to juggle kittens.

Richard recently had 15 minutes of fame when Corrina Downing, BAFTA's events manager, refused to screen his work in progress, *The Last American Freak Show*, at a joint screening with the London Disability Film Festival X08, as it made her feel uncomfortable.

"Ha! That's so patronising. Discrimination is implicit. Disabled people shouldn't be opinionated or clever. They should collect trolleys, stuff envelopes

My film is about gawping as a way of slipping another message underneath

and not go out because they get in the way, especially if they're in a wheelchair. Everyone



DAVID HARTLEY

should spend a week in a wheelchair: with only one arm, I'd go round in circles."

Freak Show follows six disabled and four non-disabled carnival performers on a six-week tour of the US. The BAFTA screening was to be an opportunity for Richard to find funding to complete the film but he is "barrelling on regardless", and says: "I see rejection as a time saving exercise. Quite frankly they did me a favour. If you tell people they're not allowed to see something, they want to see it.

"TV is like a freak show; it's about gawping. My film is about gawping as a way of slipping another message underneath. [The

troupe] have taken control of the way they're looked at. They go on stage and say: 'If you want to look at us, pay \$10.' People think that exhibiting yourself for money is fine unless you're a cripple. But these performers are doing it willingly and know what they're doing. The trouble is there's an assumption that if you've a disability, you're stupid.

"The film will work largely because the establishment don't think it will...It'll be successful. It'll be a cult film. You make something with passion and belief and

hope it gets to the zeitgeist. The younger generation – late teens, early 20s – are so different from people 20 years ago. They're the first generation to grow up with no sense of discrimination. They don't care if someone's black or disabled or a woman or whatever.

There is less stigma now [in the film industry] – but there's still discrimination. Disabled people are seen as not as capable. In fact, I can do anything any other film-maker can do: most of it better."

Richard is now working on two documentary ideas and courting interest in a feature film. "I had to make *Freak Show* to explore my relationship to my disability but I want to move on from here. I'm inspired by struggle and by revelation. I'm bursting with ideas and I'm always looking for collaborators."

• www.angelsstandcorrected.com; www.lastamericanfreakshow.com

→ Up-to-the-minute listings

For all the very latest arts listings visit www.disabilitynow.org.uk/arts

BOOK

The Ultimate Guide to Sex and Disability

T H E
ULTIMATE
GUIDE TO
SEX AND
DISABILITY

For all of us who live with disabilities,
chronic pain & illness

by Miriam Kaufman, M.D., Cory Silverberg, and Fran Odette

Wow, where to start with this review? Well, the authors weren't lying! It's excellent, absolutely the best book I've read to do with disability and sex. It covers everything I've ever heard of and much more. Every doctor and health professional should read it as part of their basic training, as well as pretty much every disabled person too.

It does have a slight bias towards the female experience but the lengths at which fellatio is joyously explained, for example, proves their commitment to an even-handed approach, and there are as many testimonies from men as woman, providing a complete manual for any reader, of whatever age, gender (including intersex, TV, etc), sexuality, and

physicality.

Starting with dispelling all those negative myths about us being asexual, undesirable, unable and undeserving of sex, etc, it slowly takes the reader through the ways of discovering one's own sexuality (very much a theme of this book; no telling how to, only explaining ways to, for the reader to decide), valuing yourself, breathing, touching, self-love, masturbation, assistance, access and all the wider implications of these factors taken into thorough and detailed account. Desire and self-esteem, diagrams, communication, copulation, oral, anal, devotees, fetishes: it has everything, really.

From anilingus and vaginal fisting to kissing, sex workers and vibrators, it leaves no stone (dildo) unturned. Finally, the list of further reading, web-sites, contacts and other info exceeds anything I've previously experienced. It's brilliant. READ IT!!!!

Mat Fraser

• *The Ultimate Guide to Sex and Disability* by Miriam Kaufman, Cory Silverberg and Fran Odette; paperback; Cleis Press; £11.99

FILM

London Disability Film Festival X08

This year's London Disability Film Festival X08, at the National Film Theatre in February, took place under a cloud. I felt that it was artistically one of the most interesting disability film festivals. Yet its organiser, London Disability Arts Forum (LDAF), has lost its Arts Council funding and so this may be its last such festival.

I arrived on the Friday to see a showing of the BBC drama from the 1980s, *The Silent Twins*, with a question-and-answer session with the screenwriter, the broadcaster Marjorie Wallace. This is a beautifully-constructed film about two isolated Welsh black twin sisters and their tragic story. The film made you rue the loss of one-off, issue-driven television plays.

I saw the shorts selection on the Saturday afternoon. Among the highlights were *Butterfly* (pictured, above), a documentary about a Scottish woman with albinism; *Stubborn and Spite*, about two disabled drivers, one of them Mat Fraser, coming to blows over a parking space; *Wheels on Fire*, about a wheelchair going on holiday independently to Blackpool; *John and Michael*, a poignant Canadian animation



about two men with learning difficulties; and *Georgina Goes Out*, a self-made film about arranging an outing as a young disabled person.

After this, there was a riveting deconstruction of the film *The Invisible Man* by the leading disability arts expert, Allan Sutherland, who noted links between lack of size, impairment and lack of power in the Cold War period.

Although I couldn't make the Sunday, I felt this was a strong, innovative festival for which Peter Kinkaid and David Watson, the two programmers, should be congratulated. It would be a pity that at a time when the event seems more vital than ever, this could be the last. LDAF ensures that the thriving London disability arts scene has a centre. Let's hope that both LDAF and the Disability Film Festival will continue.

Michael Shamash

webwatch

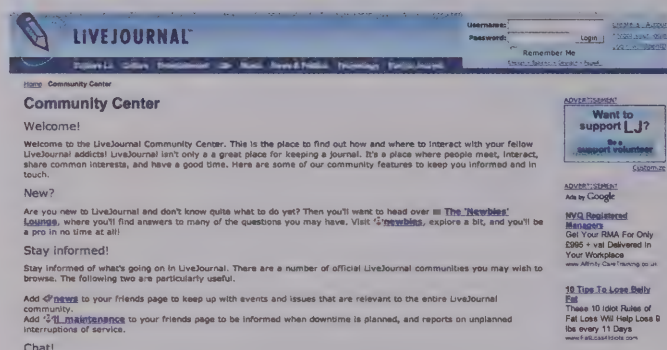
Easy as falling off a blog

Blogging can build contacts without the blogger ever leaving home, says **Penelope Fleming-Fido**

Blogging – the frequent updating of an interactive, personal, online journal – can have a special role for disabled people. Alongside a personal journal, blogging provides the means to set up online communities; becoming involved can open oneself up to a new world.

One blogger, "Isaac", says: "I got into blogging through a disability email list I was involved with. Several of the people I knew set up blogs and wrote about them on the list and I was interested enough to start one myself... I began with ready-made friends from the disabled community. Then I started joining some [other] communities and met more friends – some disabled, some not – that way."

For most bloggers who are disabled, the point of a journal is not just to talk about disability issues but what goes on in their lives. These things often overlap but usually it is tailor-made online groups that bear the brunt of specific disability talk and will be where people with disabilities go to get advice, swap tips, vent about



A blog's life: the *Live Journal* blogsite is a door to friendships

life or learn how to get politically active.

Taking a look beneath the surface of the journalling site *Live Journal*, for example, uncovers groups dealing with every aspect of disability. There are groups for specific illnesses or disabilities, activist groups, country-specific groups and groups that look at just one element of life for someone living with a disability or chronic illness.

For those who spend most of their time within the confines of their own home, there is the *Live Journal* community Homeward Bound (http://community.livejournal.com/homeward_bound). This provides contact with other people all over the world in similar

situations. It provides, in fact, a chance to gain new friends and share experiences without going outdoors.

Disabled people often have amusing or frustrating stories about their lives. *Dot Gimp Snark* (http://community.livejournal.com/dot_gimp_snark) is the place to share it – a community that comes right out with: "This isn't a support forum. Nope, this is a place for people with chronic health problems to bitch about people who refuse to 'get it'."

There is even – shock horror – a place for people to talk about that taboo area,

sex, at the community *Gimpy Sex* (http://community.livejournal.com/gimpy_sex). There are lots of sex communities all over the web, but it's refreshing to see one that caters for disabled people specifically.

Many people find that their disability has had an effect on their ability to work. *Poor Skills* (http://community.livejournal.com/poor_skills/) isn't aimed solely at disabled people but is nonetheless very appropriate. The community is welcoming and understands the fact that disability can be a root cause of poverty.

Disability groups on a blogsite act as a community within a community. By joining a "mainstream" site, disabled people get the chance to interact with others with similar issues to them but also have the option of getting to know – and maybe even educate – people whom they might otherwise never meet.

→ Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

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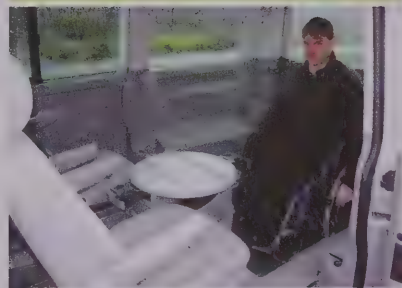


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backlash



I'm no gooseberry fool

Paul Carter takes a look at his carbon footprint – or lack of it

Unless you've been living under a rock for the past few months, you'll have noticed that there's been a lot of talk about the environment. All these buzzwords and phrases have been bandied about by all and sundry, and now every time you turn on the TV there's someone harping on about their carbon footprint like they're a world-renowned expert in geothermal physics, when in truth you know they're a housewife from Romford.

It seems that we're just not allowed to do anything anymore. You can't shop with plastic bags, drinking bottled water's a definite no-no, you certainly can't fly, and if you're spotted driving a 4x4, you'll be treated with the same level of social hatred as admitting you enjoy spending your weekends merrily kicking sacks of cats.

You're not even allowed to sit under a patio heater and enjoy a quiet pint in peace without some cardiganned weirdo with a beard and a fondness for tweed blaming you for single-handedly flooding Belgium.

Now, regular readers of my monthly tirades probably won't be surprised to know that I take objection to all of this incessant nannying. Not because I don't care about the environment – I love garden centres. The main reason I object is that, as a disabled person, I think I'm actually doing pretty well in the green stakes, thanks very much. Let me explain.

For a start – I'm only little. Being smaller than most other people, it follows logically that I take in less oxygen than others, and as a result, I give out

less CO₂, so I'm ahead of the game already.

I don't know if there's any scientific basis for this, but it fits my argument, so I'm going to run with it, metaphorically at least; actual running would probably offset my now

healthy carbon surplus, so that's out of the question.

I'm an eco-shopper too – staff at my local supermarket now know to stuff my lager and frozen pizzas into as few bags as possible. Not purely because I'm conscientious (though obviously I am), but because it's far easier for me to wobble home with a bag on each arm, even though it does make me look like a pair of scales, I absolutely refuse to get one of those little tartan trollies. (Where do people get them from anyway?)

OK, so by now we've ascertained that I'm as green as gooseberries, just by being me. That's before I say that, thanks to Ken Livingstone giving disabled Londoners free public transport, I don't even need to drive anywhere.

I'm not perfect though. I must admit to leaving my TV on standby, but that's borne out of sheer unadulterated sloth, rather than having anything to do with the fact that I can't get up and press the on switch. But come on, I've saved the planet enough for one day. I deserve to put my legs up.



CREATIVESTUDIO HEINEMANN/WESTEND61/REX FEATURES

UN Convention on the Rights of Persons with Disabilities – urge the Government to ratify it **now!**



"It's not just our citizens who will benefit from this. There are around 650 million disabled people worldwide who stand to see an improvement in their lives too – especially in the developing world where 80% of the world's disabled population lives. This convention at last puts disabled people's human rights on an equal footing with everyone else's."

Anne McGuire MP, Minister for Disabled People

Signed by the UK Government a year ago on 30 March 2007, at present the Convention is not enforceable

Scope says the UK Government should demonstrate its full and lasting commitment to disabled people's

human rights by ratifying the Convention without opting out of any of the clauses.

Take action today – urge the Government to ratify the convention by signing the petition at <http://petitions.pm.gov.uk/ratifyconvention>

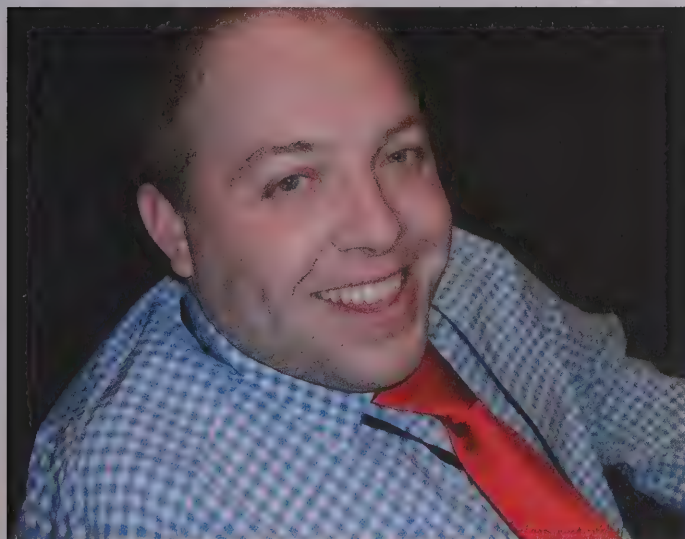
To find out more about Scope's Time to Get Equal campaign, go to www.scope.org.uk/disablism

Time to get equal

scope

About cerebral palsy
for disabled people achieving equality

worklife



Bank on it

Lloyds TSB has been ranked top of the 115 members of the Employers' Forum on Disability for its attitude to disability. **Ross Hovey**, one of its disabled managers, describes the bank's support for him since he joined

Lloyds TSB's "positive about disability" stance was important to me when I was looking at potential employers after university. I have a neuromuscular condition known as spinal muscular atrophy and scoliosis of the spine, which means I use an electric wheelchair.

There's not much my impairment stops me from doing in either my personal life or my career but I wanted to work for an organisation where there were systems in place to support me.

After joining the graduate scheme in October 2001, I made quite rapid progress. I started on the retail banking training programme and spent the first 18 months in the Cambridge area where I undertook various roles from customer services officer up to senior branch manager.

Eventually I moved to Peterborough, where I was executive assistant to the branch director.

The graduate scheme gave me an insight into the many roles on offer and meant I had time to discover

my own strengths, such as good organisation and planning. It also enabled me to see which roles best suited my lifestyle.

As a result, when I made my final move to the graduate management team, I knew I had found my niche. I was offered the role of graduate resourcing manager, wooing and selecting the best 100 graduates from a pool of more than 5,000 applications each year.

I have been there for about three years and I spend my time either in the office or out on the road, often visiting higher education institutions.

When I started in this role, I was assessed by the disability consultancy Churchill & Friend, to see what support and equipment I needed. Initially, they gave me a laptop, a mobile phone, a dictaphone, an electric stapler and an electrically-height-adjustable desk.

They also arranged for a carer to visit in my lunch hour to help me visit the gents.

When further

requirements became apparent, I was given a new electric wheelchair. The final piece of the jigsaw was a new car. With help from colleagues, friends, various charitable departments of Lloyds TSB and a grant from Access to Work, I was able to buy a fully-converted vehicle for £70,000.

I believe getting the support needed to do your job is best driven by you. Be determined, be open, ask

New things do crop up, but I know that the support is there and that all I have to do is ask. My policy in life is very simple: if you don't ask, you don't get.

While Lloyds TSB has been very supportive, things don't just happen. I believe that getting the support needed to do your job is best driven by you. Be determined, be open, ask, and always show your appreciation for support. Following this principle has failed me very few times.

ROSS HOVEY: CAREER PATH

- 2001: Graduated from Anglia Ruskin University with a 2:1 in business studies
- 2001: Joined the Lloyds TSB graduate scheme and started on the retail banking training programme
- 2003: Executive assistant to the branch director in the Peterborough area
- 2005: Graduate resourcing manager at Lloyds's head office in Gresham Street, London

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**Leonard
Cheshire
Disability**

Leonard Cheshire Disability is the UK's leading voluntary sector provider of support services for disabled people. Its annual income and expenditure is £150 million. Key challenges for the organisation are developing initiatives in new fields and building on a reputation for first class services from the existing sound base of activities. The overarching goal is to change attitudes to disability and to serve disabled people around the world. Trustees are sought who, in addition to their primary trustee roles, will assume individual responsibilities as Chairman for Scotland or Northern Ireland or Wales and the West Midlands.

The Role:

- Review services and use of assets to ensure they are consistent with the charity's mission and strategic plans.
- Act as an ambassador for Leonard Cheshire Disability, promoting volunteering and fundraising in the region.
- Chair the Regional Committee and provide advice and encouragement to the Regional Director while ensuring good links with the wider trustee body and awareness of activities in the particular country.

The Candidate:

- Experience of reviewing and commenting on strategic and operational material.
- A commitment to working to improve the lives of disabled people and to empathise with their needs.
- Willingness to speak your mind and provide leadership.

Leonard Cheshire Disability particularly welcomes applications from disabled people, women, and people from minority ethnic backgrounds.

A briefing document is available at www.odgers.com/21187 Please apply on-line, by e-mail to 21187@odgers.com or by post to the address below, quoting reference FAB/21187DN.

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RECRUITMENT

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Disability LIB is a new strategic alliance of seven organisations that have joined together to capacity build Disabled People's Organisations (DPOs) across England. The three-year project, funded by the Big Lottery Fund, comprises the Alliance for Inclusive Education, Disability Awareness in Action, Equalities National Council, People First, Preston DISC, Scope and the United Kingdom Disabled People's Council.

Scope now wishes to recruit to key posts to run this exciting new project under the direction of the alliance:

Project Director £45,000

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All posts are based in Scope's offices in London. These posts are reserved for disabled people and are for a fixed term for three years.

If you would like to find out more about working for the UK's first disability-led capacity building alliance please contact Jenny Durling on jenny.durling@scope.org.uk or 0207 619 7256 for an application pack.

The closing date is **19 April 2008**.

Time to get equal

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Charity number: 1116530

WARNING

We have been warned about a scam involving people from overseas who say they want to buy a product and who offer to pay using cheques, Western Union money transfers and certified cheques. Although no *Disability Now* readers to our knowledge have been hit by this, please be particularly wary of accepting cheques from overseas. For more information, visit the Metropolitan Police website.

DEADLINE - Disability Now

May published 26 April. Classified deadlines:

Booking: 7 April. Copy: 9 April.

EVENT

Disability Awareness Day 2008

Promoting Independence throughout Life & Work

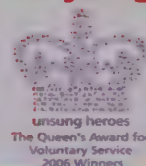
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- Post-graduate Diploma/MA in Disability and Special Educational Needs.

These new schemes have been developed to give students an opportunity to apply a disability studies perspective to a particular area of social policy and support. All our Disability Studies courses are designed for people working in or planning a career in the general area of disability policy, research and related activities.

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For further details please contact **DEBBIE WESTMORELAND** or **JESSICA LEWIS** in the School of Sociology and Social Policy at the University of Leeds, LS2 9JT.

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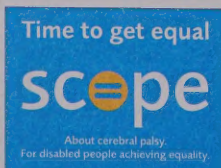


Produced by Scope in association with *Disability Now*, the quiz will help us to produce a snapshot of the lives of disabled people in Britain today. This information can be used in the battle to make things better, for **more rights**, for **more choices**, for **greater equality** and for an **end to discrimination**.



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Joan, 66



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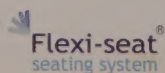
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